

REVIEW ARTICLE

Determinants of parent-delivered therapy interventions in children with cerebral palsy: A qualitative synthesis and checklist

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Abstract

Introduction: Parent-delivered therapy interventions for children with cerebral palsy can help achieve a sufficient therapy dose, improve parental mental well-being, and facilitate parent-child relationships creating a more relaxed familial environment. However, parent-delivered interventions may also lead to increased parental stress, guilt if the therapy is not delivered, and time constraints. The primary aim of this review was to gain a deeper understanding of the determinants of effective parent-delivered therapy interventions.

Method: Searches were conducted in the following databases: Medline, PubMed, Scopus, Embase, CINAHL, and Cochrane. Studies had to meet the following inclusion criteria: descriptions of parent/health care professional/child experiences of parent-delivered therapy interventions for children and young people age 0–18 years with cerebral palsy, published in the English language between January 1989 and May 2017, with qualitative or mixed methods research design. The articles were critically appraised, then synthesized using a meta-ethnographic approach.

Results: A literature search identified 17 articles, which met the inclusion criteria. Three main themes were identified: (a) building trusting relationships, (b) enabling the parents to cope, and (c) for parents and health care professionals to see the intervention as a priority. Further synthesis presented three concepts identifying the important aspects of the interventions: empowerment, motivation, and relationships.

Conclusions: The themes and concepts emerging from this qualitative synthesis can be addressed by specific points of action to support parent-delivered therapy interventions. We have summarized these in a checklist for use by intervention developers, health care professionals, and parents.

KEYWORDS

cerebral palsy, child, intervention, meta-ethnography, parent-delivered, qualitative synthesis, therapy

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1 | BACKGROUND

Cerebral palsy (CP) is a lifelong physical disorder affecting movement and posture (Rosenbaum et al., 2007). Conditions leading to CP can also affect IQ, communication skills, and be associated with epilepsy (Colver, Fairhurst, & Pharoah, 2014). Regardless of advances in perinatal care, the prevalence of CP has stayed constant over the past four decades, with estimates of 2–3 cases per 1,000 births (Oskoui, Coutinho, Dykeman, Jette, & Pringsheim, 2013).

Therapy service provision for children with CP includes supporting parents to deliver frequent, regular therapy input. This increases the therapy dose and therefore the likelihood of clinical benefit (Dirks & Hadders-Algra, 2011; Hinojosa & Anderson, 1991). Models such as “parents as teachers and therapists” have been in existence since the late 1980s (Bazyk, 1989) and have become more popular over time as a result of further supporting research. Factors such as working together with the parent, establishing cooperative goals, and tailoring the intervention to the home environment are important to the success of these interventions (Milton & Roe, 2017).

Parent-delivered intervention programmes have been piloted with a variety of patient populations, and evidence supporting their effectiveness is emerging. A highly persuasive example of an effective intervention comes from the field of autism research, namely, the Early Start Denver Model (Dawson et al., 2010), which is delivered by parents and therapists over a 2-year period, to toddlers with autism spectrum disorder. This approach was shown in a randomized controlled trial to improve cognitive adaptive behaviour compared with standard care and to ameliorate the severity of the autism spectrum disorder. Furthermore, parent-based therapy can reinforce secure parent–child attachment (Howe, 2006). In some cases, the intervention has also been found to relieve stress (Perkins & Zimmerman, 1995; von Wendt, Ekenberg, Dagis, & Janlert, 1984).

For preschool and primary school age children with unilateral CP, parent-delivered therapy was shown to lead to improvements in upper limb function (Ferre et al., 2017; Kirkpatrick, Pearse, James, & Basu, 2016). Such programmes require intensive parental support. As an example (Kirkpatrick et al., 2016), parents of 70 children aged 3–10 years with unilateral CP were supported in providing home-based activities, personalized to the child’s own interests, abilities, and level of hand function. Support included training, provision of written instructions, home visits, and regular telephone contact, plus contact for troubleshooting. The activities were undertaken for 15 min a day, 5 days a week for 3 months. Ferre et al. (2017) used a similar approach and age group but the activities (hand–arm bimanual intensive therapy or lower-limb functional intensive training) were undertaken for 2 hr/day over a 9-week period. Caregivers of the 24 children in their study were trained in administration of the assessments and the intervention; remote webcam-based supervision (1 hr/week) was also provided. For children age 4–12 years with CP, parent-delivered occupational therapy home programmes improved motor outcomes (achievement of stated goals) compared with those not receiving such programmes in a randomized controlled trial (Novak, Cusick, & Lannin, 2009). Parents undertook the intervention for around 15 min/day, 17–18 times/month for 8 weeks, with

Key Messages

- Positive reciprocal relationships between the child, therapist, and parent are a key factor in the implementation of effective parent-delivered interventions for children with cerebral palsy.
- Parents need strong support networks including support for their own needs to feel capable to deliver the intervention.
- Involved parties need to see the intervention as a priority: Motivation throughout the therapeutic process is critical to success.
- Our checklist aims to support professionals in guiding parents to implement an effective intervention.

education and guidance by occupational therapists. For infants with unilateral CP, a parent-delivered therapy adapted from the principles of constraint-induced movement therapy showed promising results for upper limb function in an initial randomized study (Eliasson et al., 2018). Parents received weekly home visits for coaching and supervision and undertook the intervention for 30 min/day, 6 days/week over a 12-week period.

In addition to the successes with parent-delivered therapy described above, there are also negative aspects of parent-delivered therapy noted within the literature. Barriers such as a lack of parental time, energy, resources, difficulties with sustainability, and increased stress levels have been reported (Lin et al., 2011). In addition, some mothers participating in such programmes have shown increased signs of depression when compared with mothers who were not taking part. In contrast, a rise in intervention hours conducted by health care professionals reduced maternal signs of depression and personal strain (Schwichtenberg & Poehlmann, 2007). It is important to consider the process of parent-delivered therapy, identifying factors that facilitate effective delivery whilst avoiding negative consequences.

In summary, there has been increasing interest in delivering home-based therapy programmes through the parents of children with CP. Although there has been a recent quantitative review of this research (Milton & Roe, 2017), to date, there has not been an attempt to review systematically and synthesize qualitative research findings exploring the determinants of parent-delivered therapy.

1.1 | Aim

The aim of this qualitative systematic review is to further explore and understand the factors that facilitate or hinder parent-delivered therapy for children with CP. The primary objective is to explore the determinants of effective parent-delivered therapy interventions in children with CP. The secondary objective is to provide a generalizable checklist based on both our findings and experience, which enables professionals and parents to see what is needed to create an effective parent-delivered therapy.

2 | METHODS

We undertook a qualitative synthesis of the literature exploring parent-delivered therapy for children with CP: This was an optimal method for exploration of the nature of barriers and facilitators to such therapy. Specifically, a meta-ethnographic review was undertaken: This rigorous approach assists researchers in going beyond summarization to produce new insights and interpretations on the topic in question (G. Noblit, 1988).

The study was split into three phases encompassing the steps within the chosen meta-ethnographic model (G. W. Noblit & Hare, 1988), namely, a systematic literature search, critical appraisal of the selected studies and synthesis of themes, and translations from the data. The protocol was registered prospectively in PROSPERO (CRD42017059985).

2.1 | Phase 1: Systematic literature search

Searches were conducted in the following databases: Medline, PubMed, Scopus, Embase, CINAHL, and Cochrane. In addition, the grey literature was studied (i.e., Google Scholar, Open Grey, and GreyLit) to reduce publication bias. The search strategy terms used can be found in Appendix S1. Additionally, during the full text review, reference chaining was undertaken, that is, the individual reference lists were searched for any additional relevant papers.

2.1.1 | Selection criteria

Studies had to meet the following inclusion criteria: (a) descriptions of a therapy intervention that had been implemented into the home environment with parental participation; child/parent/health care professional experiences of implementing programmes into their homes; parent/health care professional experiences of barriers and facilitators that may impact on the child's progress in parent-delivered home programmes. (b) Date range between January 1, 1989, and June 21, 2017. (c) Therapy aimed at children with CP at any age from the onset of diagnosis (i.e., potentially in the first year of life) to age 18 years. A wide age range was chosen given the relative paucity of literature in this field identified during scoping searches. Studies that included samples of children with motor disorders or developmental disabilities were accepted if children with CP were included. (d) Qualitative research in both qualitative studies and mixed method designs. (e) Due to limited resources for translation, this systematic review only contained studies published in the English language.

2.1.2 | Data extraction

An adapted version of an existing published qualitative research data extraction form (National Collaborating Centre for Mental Health, 2007) was used to extract data pertaining to study setting, demographics, objectives, design, data collection and analysis methods, results, and conclusions. The form was informally piloted by C. L.; data extraction from three studies using the form was reviewed with A. B. to check all relevant data were captured prior to proceeding; but no changes were deemed necessary.

2.2 | Phase 2: Critical appraisal

The appraisal tool used was the Critical Appraisal Skills Programme qualitative checklist (<http://www.casp-uk.net/>). The checklist questions were scored from 0 to 10 using a recommended approach where 10 represents a paper of the highest quality (Butler, Hall, & Copnell, 2016). However, rather than excluding studies, the quality assessment aimed to contribute to the confidence in the findings from each source (Dixon-Woods et al., 2007; Mays & Pope, 2000).

2.3 | Phase 3: Data synthesis

We used a meta-ethnographic approach to synthesize the qualitative data. First, links between the different papers were identified by looking for re-emerging themes, metaphors and concepts, and juxtaposing them against each other (France et al., 2014). Following this, we undertook a translational synthesis, that is, a comparison of concepts across the sources to lead to a more complete understanding of the identified literature (Campbell et al., 2011). We then considered how these concepts related to the broader literature in this field. Finally, these concepts were considered in relation to the target audience; thus, they will be understood in an approachable way, through the checklist we developed for health care professionals and parents.

3 | RESULTS

3.1 | Characteristics of included studies

Out of the 265 articles screened by their title or abstract, 17 were included within the synthesis (Figure 1; Table 1). These included the perspectives of 50 children, 233 health care professionals, and a minimum of 145 parents. The true number of parents may be slightly higher, as in two studies (Bloswick, Brown, King, Howell, & Gooch, 1996; Gerber, Kunz, & van Hedel, 2016), the number of families with participating parents was stated (total of 20 families), but not the number of participating parents per family. Eleven of the included studies were specific to children with CP. Of the remaining three studies, one included preterm infants (who have an increased likelihood of developing CP), another covered neuromotor disorders, and the third covered children with developmental disorders including CP. Interventions included physical therapy, occupational therapy, communication training, behavioural interventions, and music therapy.

3.2 | Critical appraisal of studies

Table 1 includes the Critical Appraisal Skills Programme quality scores for the included studies. Surprisingly, several papers did not specify whether ethical approval had been obtained. In addition, reflexivity was rarely mentioned to address whether the researchers may themselves have influenced the results or whether any strategies were implemented to reduce the risk of researcher bias. Four reports (Bloswick et al., 1996; Gerber et al., 2016; Radtka et al., 2013; Tait, Sigafos, Woodyatt, O'Reilly, & Lancioni, 2004) contained essentially qualitative descriptions without formal

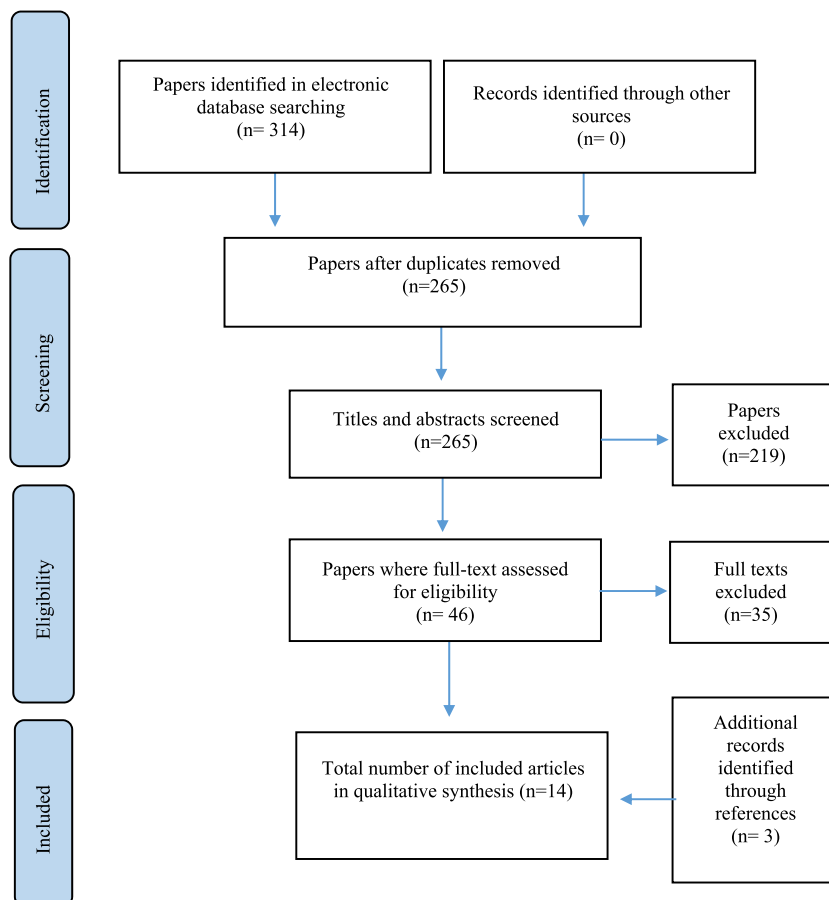


FIGURE 1 PRISMA flowchart for included studies [Colour figure can be viewed at wileyonlinelibrary.com]

qualitative analysis but were included as the content was still informative, providing contextual information about the feasibility of the interventions. One of these reports provided full text quotes from parents in an appendix (Bloswick et al., 1996); three reports provided summary descriptions of participant or parent feedback and opinions. The 13 other papers used rigorous qualitative research approaches for data collection and analysis, as summarized in Table 1.

4 | SYNTHESIS

Three themes and eight subthemes were identified. The three main themes are as follows: (a) building trusting relationships, (b) enabling parents to cope, and (c) for both participants to see the intervention as a priority.

4.1 | Theme 1: Building trusting relationships—The role of the health care professional

This theme describes the importance of the health care professional in fostering trusting relationships with the parent and child and in helping to nurture the parent–child bond.

A. Being accessible and supportive to parent and child

Where health care professionals are both accessible and supportive for the parent and child, this allows a trusting relationship to be developed. For a successful parent-delivered intervention, the health care professional must recognize the importance of an

“environment based on support, mutual trust and shared decision making” (Hinojosa, 1990; Hinojosa & Anderson, 1991; James, Ziviani, King, & Boyd, 2016; Kruijzen-Terpstra et al., 2016; Novak, 2011; Piggot, Paterson, & Hocking, 2002; Taylor, Dodd, McBurney, & Graham, 2004; Yang, 2016; quote from Kruijzen-Terpstra, p. 320).

An important method for parents to learn how to undertake interventions is for them to observe and model the health care professionals performing the interventions (Hinojosa & Anderson, 1991; Novak, 2011; Yang, 2016). This modelling is likely to occur most readily in the context of a trusting mutual relationship. When parents observe that the health care professional has a caring, loving relationship with the child, this facilitates the connection between the parent and health care professional. Thus, “parents needed to have some shared history and knowledge of the therapist’s love for and commitment toward their child” (Piggot et al., 2002, pp. 1126–1127). Such a relationship can be disrupted via a high turnover of staff (Basu, Pearse, Baggaley, Watson, & Rapley, 2017; Peplow & Carpenter, 2013; Piggot et al., 2002) or a change in the quality of support provided to the family from health care professionals (Peplow & Carpenter, 2013).

B. Strengthening the parent–child bond

When there is a clear positive parent–child relationship that facilitates “physical, interactional and emotional” aspects (Basu et al., 2017, p. 9), the likelihood of engagement from young children increases. This is further supported by Yang’s music intervention programme, which demonstrated that parent teaching strategies

TABLE 1 Summary of included papers

Author/year	Participants	Health condition	Aim	Data	Analysis	CASP Score
Basu et al., 2017	9 parents 16 HCPs	Unilateral CP	Development of a manualized, parent-delivered, home-based early therapy intervention	Focus groups and peer reviews	Normalization process theory	9.5 (High)
Bloswick et al., 1996	5 families (parents of 5 children)	CP	To determine if extended use of the hip extensor tricycle (for home use) would help children with CP	Evaluation forms	Full text of parent responses included in appendix	8.5 (Moderate)
Gerber et al., 2016	15 families (15 children and their parents)	Central motor disorders including CP	Investigate feasibility and usability of portable version of YouGrabber system (for the upper limb) in the home setting	Diaries and questionnaires	Descriptions of opinions from families	8.5 (Moderate)
Hinojosa, 1990	8 parents	CP	Mothers' perceptions of what happens when their child with cerebral palsy receives occupational/physical therapy	Interviews and observations	Exploratory ethnographic study	7.0 (Low)
Hinojosa & Anderson, 1991	(8 parents) Same dataset as above	CP	Understanding the impact of home programmes on family members by exploring their experiences and reactions	In-depth interviews; observations	Thematic analysis	9.0 (High)
Hinojosa et al., 2002	199 HCPs	CP	Identify current occupational therapists' attitudes and values in their working relationships with parents	Questionnaire (2 open-ended questions)	Thematic analysis	8.5 (Moderate)
James et al., 2016	10 children and their 0 caregivers	Unilateral CP	To understand engagement of children in a home-based computer programme (Move it to improve it)	Semistructured interviews	Inductive approach	7.5 (Moderate)
Kruijssen-Terpstra et al., 2016	21 parents	CP	Explore the experiences and needs of parents of young children (aged 2–4 years) with CP in relation to their child's physiotherapy and occupational therapy	Interviews	Thematic analysis	9.5 (High)
Novak, 2011	10 parents	CP	Identifying parent views about implementing home programmes for practical purposes	Semistructured interviews	Grounded theory	7.5 (Moderate)
Peplow & Carpenter, 2013	4 parents	CP	Explore how parents of children with cerebral palsy perceive exercise programmes	Interviews	Thematic analysis	9.5 (High)
Piggot et al., 2002	8 parents and 4 therapists	CP	Identify, describe, and generate a conceptual model of the experience of parents and therapists taking part in home therapy programmes	In-depth interviews and observations	Grounded theory	9.5 (High)
Radtka et al., 2013	14 children	Spastic CP	Demonstrate the technical feasibility, ease of use, appeal, and safety of a computer-based videogame program for children with CP	Observations	Summary of observations	7.0 (Low)

(Continues)

TABLE 1 (Continued)

Author/year	Participants	Health condition	Aim	Data	Analysis	CASP Score
Sakzewski et al., 2014	9 HCPs	Unilateral CP	Identify barriers and enablers experienced by occupational therapists when delivering upper limb interventions for children with CP	Semistructured interviews	Framework analysis	7.5 (Moderate)
Tait et al., 2004	6 parents	CP	To evaluate parent use of functional communication training for parents of children with developmental and physical disabilities	Interviews, observations, and coding	Description of behaviours	7.0 (Low)
Taylor et al., 2004	11 children and their parents (10 mothers, 3 fathers)	CP	Exploration of factors that influence adherence to a home-based strength training programme for children with CP	Interviews	Thematic analysis	8.0 (Moderate)
Whittingham et al., 2011	8 parents, 5 HCPs	CP	To explore challenges faced and the feasibility of a new intervention for children with CP	Focus groups	Thematic analysis	9.5 (High)
Yang, 2016	26 families (26 mothers, 2 fathers)	Developmental disabilities including CP	To investigate the effect of participation in a home-based music programme on parent-child interactions	Questionnaires, observations, feedback sheets	Content analyses and qualitative descriptions	9.5 (High)

Note. CASP: Critical Appraisal Skills Programme; CP: cerebral palsy; HCP: health care professional.

improved parent-child interactions. The parent teaching strategies also improved bonding within the family and parent-child synchrony (Yang, 2016). If the intervention is enjoyable and appealing to both the parents and child, this can reinforce a positive relationship between them (Basu et al., 2017; Hinojosa, 1990; Hinojosa & Anderson, 1991; Yang, 2016). Interventions run the risk of becoming damaging to the parent-child relationship when there is a lack of variety in the therapeutic activities and where the level of challenge in the activities is not pitched correctly for the child (Bloswick et al., 1996; Gerber et al., 2016; Radtka et al., 2013).

4.2 | Theme 2: Enabling parental coping

This theme explores how to help parents to feel capable of delivering the intervention and to ensure parents have strong support networks including specific coping strategies to help them manage their own needs.

C. Feeling capable

Parents sometimes struggle with intervention delivery (Hinojosa & Anderson, 1991; Tait et al., 2004); they feel "there are things that mothers do and things that therapists do" (Hinojosa & Anderson, 1991, p. 276). Parents tend to feel overwhelmed at the start (Hinojosa, 1990; Novak, 2011; Piggot et al., 2002), and when the health professionals show them more than one exercise at a time (Hinojosa & Anderson, 1991). Health care professionals and parents agree that interventions should be given in "manageable chunks" (Basu et al., 2017, p. 6) to reduce the chance of damaging parental confidence (Hinojosa & Anderson, 1991; Taylor et al., 2004). The development of parental empowerment and capability is a dynamic process; health care professionals should be aware of this dynamic process and support its growth (Kruijssen-Terpstra et al., 2016; Piggot et al., 2002). One way to help parents feel more capable is to incorporate a user-friendly approach, which fits easily into their daily routines (Basu et al., 2017; Hinojosa, 1990; Hinojosa & Anderson, 1991; James et al., 2016; Novak, 2011; Peplow & Carpenter, 2013; Piggot et al., 2002; Taylor et al., 2004).

D. Finding support

Maintaining a support network with family members and surrounding peers is crucial for parental mental health (Hinojosa, 1990; James et al., 2016; Whittingham, Wee, Sanders, & Boyd, 2011) and is a key ingredient for parental empowerment (Kruijssen-Terpstra et al., 2016; Peplow & Carpenter, 2013; Piggot et al., 2002). Piggot et al. (2002) found that one of the crucial determinants of acceptance was the surrounding "circumstantial support ... received from family and others" (p. 1123). This support provides parents with an increased sense of control (Kruijssen-Terpstra et al., 2016), a more positive outlook, and encourages them to strive to maximize their child's improvements, by increasing their participation in home programmes (Piggot et al., 2002, p. 1123). Extra support from health care professionals is often requested where parents struggle with time pressures to deliver therapy (Hinojosa & Anderson, 1991; Peplow & Carpenter, 2013). This is unsurprising given the additional daily tasks that may need

completing for a child with disability (Sakzewski, Ziviani, & Boyd, 2014; Whittingham et al., 2011).

E. Developing coping strategies

Parents of a child with CP have been found to have negative thoughts and feelings, with high levels of stress (Hinojosa, Sproat, Mankhetwit, & Anderson, 2002; Peplow & Carpenter, 2013; Taylor et al., 2004) and grief (Basu et al., 2017; Piggot et al., 2002; Whittingham et al., 2011). The combination of these feelings and a parent-delivered intervention result in high amounts of pressure, isolation (Peplow & Carpenter, 2013), and difficulty coping (Whittingham et al., 2011). Coping strategies vary depend on the stage of acceptance. During the initial phase where parents begin to come to terms with their child's disability, common coping strategies are "keeping up appearances ... [and] trying to make sense of the situation" (Piggot et al., 2002, p. 1120). As time develops, parents begin to adjust by implementing strategies such as thinking ahead, setting goals, and managing their daily demands (Piggot et al., 2002).

Parents find it hard to understand how to parent "without a benchmark" (Hinojosa et al., 2002, p. 1563) as the developmental trajectory of their child is less certain when they have CP (Hinojosa, 1990; Novak, 2011; Whittingham et al., 2011). Thus, another way to help parents cope is to provide as much explanation and information as possible, paced to their readiness to accept it.

4.3 | Theme 3: The intervention as a focus

The third theme identified specific aspects of the intervention that should be optimized to facilitate delivery. These were provision of appropriate training and resources, tailoring of the intervention to the family's needs, and seeing improvements because of the intervention.

F. Training and resources

Parents and health care professionals need appropriate training and education regarding the purpose of the intervention and in delivery (Sakzewski et al., 2014). Parents were keen to receive such education, and in several studies, they requested more materials in different formats (Basu et al., 2017; Taylor et al., 2004), training courses to assist with therapy implementation (Peplow & Carpenter, 2013), and the correct resources within the home to complete the therapy (Taylor et al., 2004). Parents often struggled regarding whether to attribute disruptive behaviours to their child's condition or not and wanted professional advice on behaviour management (Whittingham et al., 2011). Lack of motivation, unresponsiveness to encouragement, and using tactics to avoid therapy were three of the main child behaviour problems, requiring increased effort from parents to complete interventions (Gerber et al., 2016).

G. Tailoring to the family

Parents found it important to tailor the intervention to the child's age, cognitive/physical disability, individual traits, and functional levels (Gerber et al., 2016; James et al., 2016; Novak, 2011; Radtka et al., 2013; Sakzewski et al., 2014; Whittingham et al., 2011; Yang, 2016). Parents also expressed a wish to modify the

intervention to fit their differing parenting strategies and styles, personal beliefs, and environmental situations (Gerber et al., 2016; Peplow & Carpenter, 2013). Some parents preferred a flexible approach, whereas others were comfortable with strict adherence (Peplow & Carpenter, 2013). In practice, some interventions may offer little scope for flexibility.

H. Knowing that the intervention works

Parents and children were highly internally motivated to achieve positive outcomes from interventions (Basu et al., 2017; James et al., 2016; Whittingham et al., 2011); seeing improvements from an intervention was the main external motivation for continuing with it (Hinojosa, 1990; Piggot et al., 2002; Taylor et al., 2004). Without this, parents tend to display a lack of effort in performing the intervention, reduced attendance at the therapy sessions, and reduced faith in the health care professional (Hinojosa et al., 2002). Factors such as malfunctioning equipment (Gerber et al., 2016; Taylor et al., 2004) resulted in parents seeing the intervention as a burden.

5 | A MODEL TO IDENTIFY THE FACTORS WHICH INFLUENCE THE SUCCESS OF PARENT-DELIVERED THERAPY

From the current synthesis, we undertook a second level of synthesis to identify common concepts across the themes described above (G. Noblit, 1988). This led to the derivation of a model identifying and interlinking the factors influencing the success of parent-delivered therapy. The three main factors identified were empowerment, motivation, and the reciprocal relationships between the parent, child, and health care professional. These factors together underpin all the themes and subthemes identified. Motivation encompasses the theme "the intervention as a focus": tailoring, training, and knowing that the intervention works will enhance motivation, though internal motivation is also crucial. Empowerment encompasses the theme "enabling parental coping" but interacts with motivation (including motivation of the health care professional to support and empower the family). The factor "reciprocal relationships" encompasses the theme of "building trusting relationships" and underpins both motivation and empowerment. Figure 2 provides an accessible summary of the model, emphasizing the links between parental empowerment, motivation of all parties, and strongly positive reciprocal relationships between the parent, child, and health care professional.

5.1 | Empowerment

Within the synthesis, the theme "enabling parental coping" encompassed having a well-configured support network, coping strategies, and capability, which all facilitated the parental empowerment process. This also had a positive effect on motivation and reciprocal relationships. This empowerment process is facilitated if the intervention is easy to use. Furthermore, health care professionals need to help parents come to terms with their child's disability, which is a crucial stage of the empowerment process.

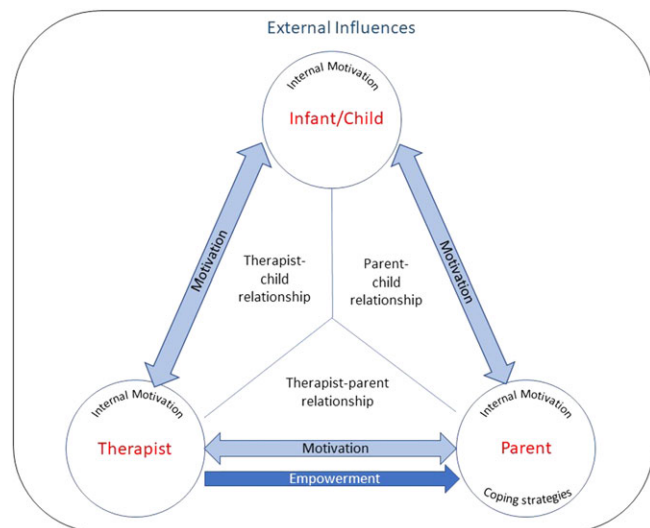


FIGURE 2 Model of influences on parent-delivered therapy identified from meta-ethnographic analysis [Colour figure can be viewed at wileyonlinelibrary.com]

5.2 | Motivation

Motivation was described as a key facilitator of parent-delivered therapy. Motivation increased when parents saw the intervention as a priority, when appropriate training and resources were provided, and when the intervention was seen to be effective. This is likely to have a beneficial effect on the health care professional, reinforcing positive interactions with the parent and child.

5.3 | Reciprocal relationships

Positive, trusting reciprocal relationships between the parent, child, and health care professional facilitate successful interventions. Evident lack of knowledge on the part of the health care professional may lead to a breakdown of trust; high staff turnover can hinder the formation and maintenance of strong positive relationships with families. Health care professionals need to view their role as consultancy-based with explanation, guidance, and reassurance for parents as the most constructive approach. Parents also value and trust a health care professional who develops a good relationship with their child; this facilitates the modelling of positive behaviours observed in the health care professional by the parent. Finally, having a successful parent-delivered intervention reinforces further positive engagement between the parent and child.

6 | DISCUSSION

Several factors influence the success of parent-delivered therapy. Key to this success are building trusting relationships, enabling parental coping, and for all to focus on the intervention as a priority. The overarching concepts emerging from our review were empowerment, motivation, and positive reciprocal relationships between the parent, child, and health care professional. The focus of the discussion is the significance of these findings in relation to the broader literature.

6.1 | Empowerment

Empowerment has been described as “a process by which individuals gain mastery and control over their lives and a better understanding of their environment” (Zimmerman Marc, Israel Barbara, Schulz, & Checkoway, 1992). In the context of a child with disability, parental empowerment has been described as encompassing coping within the family, fully utilizing available local services, and having a comprehensive awareness of the structure of services available to the community more broadly (Koren, DeChill, & Friesen, 1992). Perkins and Zimmerman (1995) state that “empowerment-oriented interventions enhance wellness while they also aim to ameliorate problems, provide opportunities for participants to develop knowledge and skills, and engage professionals as collaborators instead of authoritative experts” (p. 570).

The concept of developing parental empowerment is critical and is gaining recognition and credence (Dirks & Hadders-Algra, 2011). An interventional approach that fits into the family routine facilitates confidence, capability, and empowerment (Chen, Pope, Tyler, & Warren, 2014; Itzhaky & Schwartz, 2001). Health care professionals should also recognize where families have little social support, which may adversely affect empowerment, and provide their own professional contribution towards facilitating parental empowerment (Hall et al., 2012; Milton & Roe, 2017).

Parental empowerment may change over time and will also depend on how well the parent is coping internally (Vig & Kaminer, 2003). Thus, every parent may be at a different stage of personal empowerment that may affect the success of the parent-delivered therapy, as well as contributing to the differing levels of stress experienced by parents when implementing therapy (Schwichtenberg & Poehlmann, 2007). Where there are specific concerns, as well as in research settings, the Family Empowerment Scale (Koren et al., 1992) may be a useful tool to understand whether further psychological support is needed.

6.2 | Motivation

Motivation in the context of therapy can be defined as “an intrinsic psychological force that encourages the individual to attempt to master skills that are at least moderately challenging to them” (Majnemer, 2011). To master the skill, persistence, pleasure in the task, and a resilient response to failure are valuable attributes (Majnemer, 2011). This internal motivation can be influenced by external factors such as finding ways to make the intervention pleasurable. Both the parent and the child are likely to feel more motivated in the context of an intervention that is effective and deliverable as well as being suited to and tailored to their needs and goals (Carver et al., 2003; Dawson et al., 2010; Milton & Roe, 2017). An initial interview to explore and enhance parental motivation, appropriate education and training, and diaries to promote observation of progress are all helpful approaches (Bazyk, 1989; Milton & Roe, 2017; Novak, 2011). Where appropriate, and in research settings, the child's degree of mastery motivation can be assessed formally using the Dimensions of Mastery scale (Miller, Marnane, Ziviani, & Boyd, 2014).

A potentially valuable approach is motivational interviewing: This is “is a collaborative conversation style for strengthening a person's

own motivation and commitment to change" (Miller & Rollnick, 2013, p. 21). Similarly, solution-focused coaching (Baldwin et al., 2013), defined as a "strengths-based, relational, and goal-oriented approach ... that uses positive reframing and strategic questions to assist clients in envisioning a preferred future and developing practical solutions to move toward this vision," is another approach that is likely to enhance both motivation and empowerment. It has been suggested that motivational interviewing and solution-focused coaching can help parents to take control over the intervention delivery (Eliasson, Sjostrand, Ek, Krumlinde-Sundholm, & Tedroff, 2014). It would be beneficial for health care professionals to be trained in the use of motivational interviewing and coaching strategies given their role in helping parents with goal setting, planning, and intervention delivery, though further research is required to evaluate and optimize the use of these approaches (Kessler & Graham, 2015).

6.3 | Reciprocal Relationships

Applying a successful parent-delivered intervention is a complex procedure that needs trusting reciprocal relationships between the parent, health care professional, and child. If delivered correctly, the parent-delivered intervention can augment the parent-child relationship due to increased interaction and bonding time (Chen et al., 2014; Ferre et al., 2017). Conversely, if insecure attachments and difficult life events are prominent factors within a family, enhanced support may be needed. The Parent-Child Interaction Questionnaire (Lange, Evers, Jansen, & Dolan, 2002) or, for infants, the Parent-Infant Interaction Observation Scale could be used to assess the parent-child relationship (Svanberg, Barlow, & Tigbe, 2013).

A positive relationship between the parent and health care professional is crucial (Novak & Berry, 2014). It may also help improve the fidelity of the intervention through observation and replication of the actions of the health care professional by the parent (Ferre et al., 2017); the health care professional may also model positive interactional behaviours with the infant or child (Basu et al., 2017). Lastly, a positive relationship between the health care professional and the child is also likely to be highly relevant to the success of the intervention (Milton & Roe, 2017). Within the current qualitative analysis, only one paper identified the importance of this relationship: Parents commented on how it improved both their relationships with their child and with their health care professional (Piggot et al., 2002).

6.4 | Clinical implications

Key practical issues arising from this review were used to create a suggested checklist designed for health care professionals and parents (Appendix S2). This will provide a quick and accessible instrument to use when initiating the intervention and to ensure continuing improvements via reflection. It should be stressed that this is a prototype, which can be tailored to specific intervention contexts. We are also aware that resource constraints (particularly in terms of finances, time, and other job pressures) limit what can be done and that ongoing therapist input with new ideas and challenges tailored to the right level for the child is a key factor in maintaining motivation in practice.

Further iterations of the checklist are likely and encouraged following evaluation of its use: We will be piloting the checklist in future work.

6.5 | Strengths and limitations

The strengths of our study include a rigorous approach and input from a team with experience in developing and supporting parent-delivered interventions. Our findings, though reached through a different process, are in line with those of Novak and Berry (2014) but additionally reinforce the importance of strong positive reciprocal relationships between the parent, child, and health care professional.

Some limitations of the study must be mentioned. First, we restricted our dataset to papers written in the English language and thus may have missed some further relevant literature. Second, although our findings may be relevant to parent-delivered interventions for children with a range of neurodevelopmental disabilities, generalizability may be limited to first world health care systems.

The paper also highlights avenues for future research and suggests some weaknesses that should be addressed in future similar studies: For example, the experiences of fathers and other family members are rarely captured (Carpenter & Herbert, 1997), and the views of children are under-represented in comparison with those of parents and therapists. Furthermore, although challenging, it would be useful to obtain more feedback from families who discontinued interventions to identify barriers that could be overcome in future. It would also be valuable to determine whether using a structured checklist improves clinical practice and facilitates higher adherence to, and successful completion of, interventions.

7 | CONCLUSIONS

This review aimed to identify determinants of parent-delivered therapy and by taking these into account, create a checklist for health care professionals and parents. The checklist encompasses the three overlapping constructs: empowerment, motivation, and reciprocal relationships, which were derived from the main themes (building trusting relationships; seeing the intervention as a focus; enabling parental coping). The main goal of parent-delivered therapy is to create enough input for the child to have the best chance in improving their disability. It is crucial for health care professionals to understand the issues raised in this paper, so they can help maximize the effectiveness of parent-delivered therapy.

CONFLICTS OF INTEREST

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DECLARATIONS

The authors declare that the work submitted is their own and that copyright has not been breached in seeking its publication. Clarissa

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