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Effectiveness of peer support programmes for improving well-being and quality of life in parents/carers of children with disability or chronic illness: A systematic review

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Abstract

Aim: This systematic review synthesized quantitative evidence from the past decade of the effectiveness of peer support programmes in improving the well-being and/or quality of life (QoL) for parents/carers of children with disability/chronic illnesses.

Background: For children with disability or chronic illness, parents/carers are critical in enabling or limiting their child's development. The parent's/carer's ability to provide the necessary responsive and structured care is impacted by several factors, including their own personality, skills, resources and well-being. Peer support programmes often aim to build parent/carer and/or family capabilities. Although studies and reviews have found positive benefits arising from such programmes, the impact of such programmes, specifically on well-being and QoL, is unknown

Results: Quantitative studies published between 2011 and 2020 that examined the impact of programmes with a significant peer support component on parental/carer well-being, QoL and/or distress were identified from four databases and were searched and yielded 3605 articles, with 13 articles meeting the inclusion criteria. The results suggested that peer support is effective for reducing distress and improving the well-being and QoL among parents of children with disabilities; however, the evidence is limited by a high risk of bias in the included studies.

Conclusions: Although existing evidence suggests that programmes for parents/carers with a significant peer support component are beneficial for well-being and QoL, rigorous methodologies are needed in the future to gain a better understanding of the benefits of such programmes.

KEYWORDS

carers, children with disability, parents, peer support, quality of life, systematic review, well-being

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1 | INTRODUCTION

Children with disability or chronic illness have specific needs that require intentional and responsive support to enable healthy child development. Although parents/carers may willingly adopt the caregiving role, the additional challenges and stresses of that care, often combined with limited skills, resources and support, place parents/carers and their family at great risk of experiencing various stressors, impaired functioning, poor well-being and reduced quality of life (QoL) (Bhopti et al., 2020).

Well-being, QoL and psychological distress have been defined in a number of ways across disciplines, including objective and subjective indicators (Chia et al., 2020). These concepts are related and can be considered both overlapping and distinctive constructs. For the purpose of this review, QoL is defined as a sense of well-being and lack of distress that arises collectively through the dynamic interaction of individual and family-member needs (Zuna et al., 2011). Well-being is defined as feeling and functioning well across a number of domains (e.g. physical, mental, emotional and social) (Kern et al., 2020), and distress is defined as 'a state of emotional suffering characterized by symptoms of depression and anxiety' (Drapeau et al., 2012, p. 123). Various factors impact upon individual and family well-being, distress and QoL, including the fulfilment of physical and psychological needs (Deci & Ryan, 2008); individuals' personalities, attitudes, beliefs and flexibility (Bhopti et al., 2020); broader factors including the home environment and the local neighbourhood; as well as broader policies, norms and cultural beliefs (Kern et al., 2020); and disability-related support and resources (Bhopti et al., 2016).

Since the introduction of the family-centred model in the 1980s, there has been a shift in emphasis towards family-centred services and research and recognition of the inherent capacity of families (Turnbull & Turnbull, 2002). Family-centred practice, the major practice framework when working with children with developmental delays and disabilities, acknowledges that effective care not only focuses on the cause of the stressor but also identifies and builds on the family strengths to support family functioning (Dunst & Trivette, 2009). Establishing methods to develop parents' capacity and to enhance well-being and QoL is essential to fully support the development of children with disability (Bailey et al., 2006).

Peer support refers to the support provided via social networks by other people who are in a similar situation or share similar experiences and works by fostering social connections and relationships between participants (Sartore et al., 2013). Peer support is different to other forms of support because peers share personal characteristics, circumstances and/or experiences (Simoni et al., 2011). Peer support can be informational, emotional and/or instrumental; use a range of approaches (e.g. face-to-face groups, online groups and mentoring); occur through various mediums (e.g. community organizations and online); and include a variety of roles (e.g. educators and mediators) (Faulkner & Basset, 2012).

Although peer support often acknowledges parental strengths and capabilities parents have to offer, it is unclear whether peer support offered through group programmes for parents of children with

Key messages

- Peer support interventions are associated with increased well-being and quality of life (QoL) outcomes for parents and caregivers and support current practices.
- There is a need for more rigorous studies in this area to inform the design of programmes that meet the needs of families and caregivers in the future.

disabilities lead to measurable improvements in well-being and QoL. Shilling et al. (2013) conducted a systematic review of nine studies, finding qualitative evidence to suggest a range of benefits of such programmes. In addition, this review concluded that evidence available from quantitative studies was limited, with existing studies having small sample sizes and inconsistent findings. Furthermore, the review did not focus specifically on parent/carer well-being and QoL outcomes. The current review aimed to systematically examine quantitative studies published in the last decade reporting on well-being and QoL outcomes of programmes for parents/carers of children with disability and/or chronic illness that included a significant peer support component.

2 | METHODS

We conducted a systematic review of the literature that was prospectively registered on the PROSPERO database (Registration Number CRD 42020210153) and reported using the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines (Page et al., 2021).

2.1 | Search strategy

The search strategy included two elements: the population (adults who are parents/carers of a child with disability or chronic illness) and the intervention (peer support group programmes). These search concepts were consistent with a previous systematic review conducted in this area published by Shilling et al. (2013). A search was conducted on the A+ Education, CINAHL, Embase, MEDLINE, OTseeker, PsycINFO and Cochrane Central Register of Controlled Trials databases, and the publication dates were limited to the period from January 2011 to October 2020. The search strategy is summarized in Table 1.

2.2 | Inclusion and exclusion criteria

Studies that involved parents/carers of children with disability/chronic illness that investigated outcomes associated with a group-based intervention containing an explicit peer support component, and were delivered in a community or online setting and also included

TABLE 1 Summary of search terms

Element 1: Population	Element 2: Intervention
At least one of ... parent* mother father caregiv* carer*	At least one of ... group program* parent* group "support group**" mother* adj2 group support adj2 group father* adj2 group* parent* adj2 group parent* adj2 support mum* adj2 group* dad* adj2 group*
AND	AND
At least one of ... child* pediatric paediatric* infant* youth* adolescen*	At least one of ... peer "parent to parent" parent* adj2 led link* adj2 mothers link* adj2 fathers link* adj2 parents

at least one quantitative outcome measure of well-being or QoL were included. Any study design that reported within or between group comparative data was eligible for inclusion, including studies with an independent control group, randomized controlled trials or single-group pre-intervention-post-intervention studies. Studies conducted with parents/caregivers of infants in intensive care were excluded as treatment in this setting is not necessarily associated with a chronic condition. Although there was no specific age threshold to define 'children', the current study aimed to explore peer support programmes within paediatric settings; therefore, studies that were limited to only parents of adult children were excluded.

2.3 | Selection of studies

All titles and abstracts identified in the search were screened against the inclusion and exclusion criteria independently by two researchers using a web-based platform (Covidence.org, 2017). For articles potentially meeting the inclusion criteria, full-text articles were retrieved and assessed against the inclusion and exclusion criteria independently by two authors. Screening conflicts and discrepancies were resolved through consultation to reach consensus, with other authors brought in where needed to reach full consensus.

2.4 | Data extraction and analysis

For articles meeting the inclusion criteria, the authors, year, study design, setting and population, description of intervention, comparison data and data collection points, outcome domain, tool used to measure the outcome, general outcome of interest, summary of findings of outcomes tools, direction of effects and a summary of the

TABLE 2 Assessment of bias per domain

Domain	Low-risk assessment
1. Randomization process	Random assignment to group using a concealed method
2. Deviation from intended method	Participants, and those who delivered the intervention, were not aware of their assigned intervention, or there were no deviations from the intended intervention that were likely to affect the outcome as a result of lack of blinding
3. Missing outcome data	Data were not missing from all, or nearly all of participants; missing data would not impact on outcomes gained
4. Measurement of the outcomes	Appropriate outcome measurements were used, and the study used either blinded assessors or self-reported outcomes
5. Selection of reported results	Risk-of-bias assessment considered whether the analysis was reported in accordance with a pre-specified analysis plan and risks associated with the use of multiple outcome measures and analyses within the same domain

Source: Adapted from Sterne et al. (2019).

findings were recorded in an Excel spreadsheet (available upon request). Data were organized into a table for descriptive analysis. A meta-analysis was not conducted, due to the low quality of reporting and heterogeneity of the included studies.

2.5 | Assessment of risk of bias

For each included study, two authors (KL and KH) independently assessed the risk of bias using the Cochrane Risk of Bias 2 (RoB 2) tool (Sterne et al., 2019). This tool was originally developed for assessing bias in randomized controlled trials. The interpretation of criteria for other study designs included in the current review is summarized in Table 2.

3 | RESULTS

3.1 | Yield

Our search identified 3605 citations, resulting in 2587 papers for screening after removal of duplicates. After title and abstract screening, 2501 papers were excluded (Figure 1), with full-text papers sought for the remaining 86 studies. A further 74 studies were excluded, resulting in 12 studies that met the inclusion criteria. The most common reasons for exclusion were an ineligible publication type [such as a conference abstract ($n = 26$), interventions with no peer support or group component ($n = 15$) or interventions with no quantitative outcomes reported ($n = 12$)]. One additional study was identified through reference and citation checking of the included studies (Lunsky et al., 2018) reporting additional data from a study

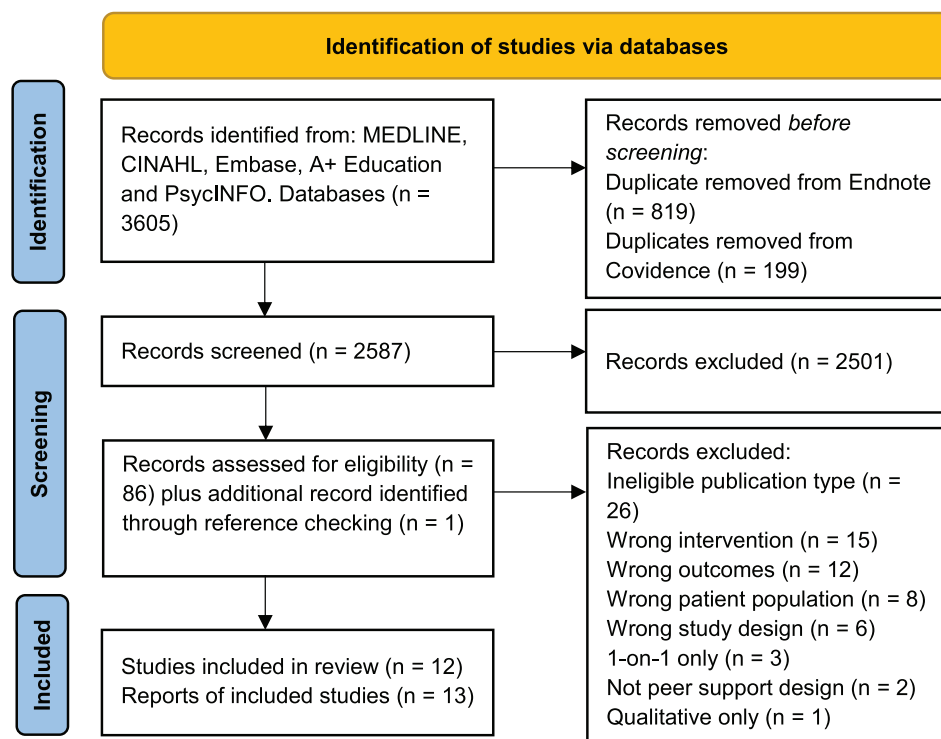


FIGURE 1 PRISMA flow chart

previously identified for inclusion (Fung et al., 2018), making a final library of 13 articles reporting on 12 studies (Table 3).

3.2 | Characteristics of included studies

The majority of the studies ($n = 10$) used post designs (Akre et al., 2015; Blake et al., 2019; Borek et al., 2018; Bray et al., 2017; Dababnah & Parish, 2016; Fung et al., 2018; Martin et al., 2019; Mills et al., 2021; Niinomi et al., 2016; Wilford et al., 2020), and there was one randomized controlled trial (Boogerd et al., 2017) and one study with a non-randomized comparison group (Stuttard et al., 2016) (Table 3). These studies were conducted across multiple countries, including the United Kingdom ($n = 5$) (Blake et al., 2019; Borek et al., 2018; Bray et al., 2017; Martin et al., 2019; Stuttard et al., 2016), Canada ($n = 3$) (Fung et al., 2018; Lunsy et al., 2018; Mills et al., 2021) and the United States ($n = 2$) (Dababnah & Parish, 2016; Wilford et al., 2020), and included a total of 556 participants. The most common diagnosis of the children requiring care was autism spectrum disorder (ASD) ($n = 6$ studies) (Dababnah & Parish, 2016; Fung et al., 2018; Lunsy et al., 2018; Mills et al., 2021; Niinomi et al., 2016; Stuttard et al., 2016). Three studies described the needs of the children in more general terms such as additional needs or disability (Borek et al., 2018; Bray et al., 2017; Martin et al., 2019), and the remaining three evaluated interventions for parents of a child with diabetes (Boogerd et al., 2017), cancer (Wilford et al., 2020) and a variety of chronic illnesses (Akre et al., 2015). The interventions included peer-led parent programmes or were interventions that contained an element of peer support. Six studies included interventions that were completely peer led (Blake et al., 2019;

Boogerd et al., 2017; Bray et al., 2017; Fung et al., 2018; Martin et al., 2019; Mills et al., 2021). The other studies reported on interventions that were expert facilitated and included an element of peer support. The duration of programmes varied from 1.5 days to 6 months, and many of the interventions were held weekly or fortnightly ($n = 9$) (Akre et al., 2015; Blake et al., 2019; Borek et al., 2018; Bray et al., 2017; Dababnah & Parish, 2016; Martin et al., 2019; Mills et al., 2021; Stuttard et al., 2016; Wilford et al., 2020). Interventions were held in community health settings.

3.3 | Risk of bias

As summarized in Figure 2, all the studies included in the review were assessed as having one or more areas of risk of bias. Only one study (Boogerd et al., 2017) included random allocation to groups (Domain 1). Half of the studies deviated from the intended outcomes (Domain 2), and three studies had missing outcome data (Domain 3). In all studies, there were concerns regarding the measurement of outcome (Domain 4), mostly due to the study design where assessors were aware of the intervention that participants had received. All but one study (Boogerd et al., 2017) had at least some concerns about the risk of bias for selection of the reported results (Domain 5), mostly due to the lack of a pre-specified analysis plan.

3.4 | Study findings

Across the studies, there were 27 different measurement tools used to quantify outcomes for participants. Outcome measures were

TABLE 3 Characteristics of articles included in review

Author, year and location	Study design	Setting and population	Intervention description	Comparison data	Method to measure outcomes and data collection points
Akre, 2015, Switzerland	Two-phase pretests–post-tests of intervention	Parents of children from five specialized paediatric hospital clinics who have a child with a chronic illness ($n = 29$)	4 × 2-h modules held fortnightly; three modules delivered by clinician, and fourth module facilitated peer support	Baseline scores	Online questionnaires completed before intervention (T0), after intervention (T1) and Group 1 at 6 months and Group 2 at 4 months, after end of intervention (T2)
Blake, 2019, UK	Mixed-methods study of pre-intervention–post-intervention	Parents of a child with additional needs, recruited across four geographical settings as either a befriender ($n = 33$) or befriender ($n = 33$)	Face2Face programme: Trained parents ‘befrienders’ provide peer support to ‘befriender’ 1:1 support in six sessions over several months; ongoing ‘drop-in’ group support sessions	Baseline scores	Telephone survey conducted at two time points: T1 – at recruitment and T2 6–9 months later
Boogerd, 2017, the Netherlands	Randomized controlled trial	Parents of children (<13 years) with diabetes ($n = 107$)	Sugarsquare programme: Web-based patient portal with peer support provided via chat function, forum and blog. Participants accessed intervention for 6 months in addition to usual care	Usual-care group	Online survey completed at baseline, start of study (T0), 6 months after start of study (T1) and 12 months after start of study (T2)
Borek, 2018, UK	Pretest–post-test of intervention	Parents and caregivers ($n = 7$) of a child (<25 years) with additional needs or disabilities	Healthy Parent Carers (HPC) programme: Six weekly sessions. Peer support facilitated by expert	Baseline scores	Questionnaire completed before intervention, at the end of the programme and 2-month follow-up
Bray, 2017, UK	Pretest–post-test of intervention	Recruited participants are parents of a child with a disability attending an acute children’s tertiary hospital setting. Participants were allocated as either befrienders ($n = 12$) or befrienderes ($n = 26$)	Face2Face programme: Trained parents ‘befrienders’ provide peer support to ‘befriender’ for 8 × 1:1 session, befrienderes supported in groups	Baseline scores	Questionnaire completed (by both befrienders and befrienderes) before intervention (T1) and at the end of the intervention (T2)
Dababnah, 2016, USA	Pretest–post-test study	Parents of a child (3–6 years) with autism spectrum disorder (ASD) ($n = 17$)	Incredible Years Program: 15 × 2-h weekly sessions. Expert led with regular peer support component each session	Baseline scores	Data from parent stress survey collected pretest and post-test

(Continues)

TABLE 3 (Continued)

Author, year and location	Study design	Setting and population	Intervention description	Comparison data	Method to measure outcomes and data collection points
Fung, 2018, Canada	Pretest–post-test study	Mothers of a child (<22 years) diagnosed with ASD ($n = 33$)	Acceptance and commitment therapy (ACT) group intervention: Trained parents provide 1.5-day group intervention with 1-month refresher session	Baseline scores	Data from participants via online questionnaire 1 week prior to intervention, 1 month post-intervention (pre-refresher) and at 3 months post-intervention
Lunsky, 2018, Canada	Pretest–post-test study	Mothers of a child (<22 years) diagnosed with ASD ($n = 33$)	Acceptance and commitment therapy (ACT) group intervention: Trained parents provide 1.5-day group intervention with 1-month refresher session	Baseline scores	Data from participants via online questionnaire 1 week prior to intervention, 1 month post-intervention (pre-refresher) and 3 months post-intervention
Martin, 2019, UK	Pretest–post-test study	Parents of a child (3–28 years) with a disability ($n = 108$)	HOPE Programme: 6 × 2.5-h weekly sessions. Parents trained as facilitators for group sessions	Baseline scores	Data collected from questionnaires completed at baseline and post-programme
Mills, 2021, Canada	Pretest–post-test	Parents of a child (3–25 years) with ASD ($n = 63$)	Community and Regional Economic Support (CARES) programme: Peer-facilitated group programme of 6 × 1-h weekly sessions	Baseline scores	Participant data obtained via questionnaires completed at intake, prior to programme and 1 week following programme completion
Niinomi, 2016, Japan	Pretest–post-test	Parents of a child (42–150 months) with ASD ($n = 24$)	Skippu-Mama: Five groups, each group ($n = 4–8$) completes 6 × 2-h monthly sessions. Appears to be expert led with three sessions focused on parents and peer interaction	Baseline scores	Outcomes were measured via questionnaires completed at pre-programme, 3 months into programme and at 6 months (after completion)
Stuttard, 2016, UK	Non-randomized controlled study	Parents of a child (5–17 years) with ASD ($n = 35$)	Cygnnet programme: 6 × up to 3-h weekly sessions, with 6-week follow-up session. Six weeks later with a maximum group size $n = 12$ with informal and voluntary follow-up 6 weeks later. Appears to be expert led with peer support component in each session	Waitlist control group	Outcomes were measured via questionnaires at pre- and post-intervention and 3-month follow-up

TABLE 3 (Continued)

Author, year and location	Study design	Setting and population	Intervention description	Comparison data	Method to measure outcomes and data collection points
Wilford, 2020, USA	Pretest–post-test and follow-up	Parents of a child (6 months to 14 years) with a brain tumour (n = 12)	Ohana Project: 12-week programme that includes moderated Facebook page, weekly group for parents and their children and weekly group for parents only. Sessions and social media were peer led with an information session run by a clinician	Baseline scores	Data were collected via surveillance of intervention adherence and participation and also online questionnaires given to participants 1 week prior to start of intervention (T1), the week following intervention completion (T2) and 3 months post-intervention (T3)

Study ID	D1	D2	D3	D4	D5	Overall	
Akre2015	-	-	-	!	!	-	+ Low risk
Blake2019	-	+	-	!	-	-	! Some concerns
Boogerd2017	!	-	-	!	+	-	- High risk
Borek2018	-	!	+	!	!	-	
Bray2017	-	+	+	!	!	-	D1 Randomisation process
Dababnah2016	-	+	+	!	!	-	D2 Deviations from the intended interventions
Fung2018	-	!	+	!	!	-	D3 Missing outcome data
Martin2019	-	!	+	!	!	-	D4 Measurement of the outcome
Mills2021	-	+	+	!	!	-	D5 Selection of the reported result
Niinomi2016	-	+	+	!	!	-	
Stuttard2016	-	+	!	!	!	-	
Wilford2020	-	!	+	!	!	-	
Lunsky2018	-	!	+	!	!	-	

FIGURE 2 Risk of bias

grouped into similar psychological aspects under the following three themes: (i) distress (anxiety/depression, $n = 6$ studies; stress/distress, $n = 7$ studies), (ii) well-being (well-being, $n = 4$ studies; elements of well-being, $n = 6$ studies) and (iii) QoL ($n = 5$ studies). Outcome measures and key findings for each study are summarized in Table 4.

3.4.1 | Distress

Six studies included measures of anxiety and depression. Studies consistently reported reductions in anxiety/depression, with six studies (Borek et al., 2018; Bray et al., 2017; Fung et al., 2018; Lunsky et al., 2018; Martin et al., 2019; Mills et al., 2021) finding statistically significant reductions.

Seven studies included measures of stress, with mixed results. Four measures reported in three studies found statistically significant reductions in stress, and Niinomi et al. (2016) reported observed reductions in stress associated with participation in a peer support group intervention, although these differences did not reach statistical significance. In contrast, Akre et al. (2015) and Boogerd et al. (2017) found no difference in measures of stress associated with participation in a peer support intervention.

3.4.2 | Well-being

Four studies directly measured well-being using three different outcome measures and showed a significant improvement in well-being

TABLE 4 Outcome data from each study

Themes	Measures	Author	Findings	Direction of effect	Summary of findings
Distress Anxiety and depression	PHQ-9	Borek, 2018	Decrease in depression scores ($P < 0.05$)	✓	Consistent reduction in anxiety and depression over six observational studies for parents completing (peer) support programmes
	DAASS-21	Lunsky, 2018	Decrease in score ($P < 0.01$)	✓	
		Mills, 2021	Decrease in levels of depression ($P < 0.01$), $r = 0.37$	✓	
	HADS	Martin, 2019	Improvement in scores ($d = 0.81$, $P < 0.0001$)	✓	
	GHQ-12	Bray, 2017	Improvement for befriendeds, ($P < 0.016$) and observed improvement for befrienders ($P < 0.072$)	✓	
	CFQ	Fung, 2018	Improvement in scores ($P = 0.001$)	✓	
	PSS	Akre, 2015	Improvement from T0 to T1 ($P = 0.5$) and worsening from T0 to T2 ($P = 0.61$)	×	
		Mills, 2021	Stress scores reduced ($P < 0.01$, $d = 0.26$)	✓	
		Boogerd, 2017	No significant change was found ($P = 0.49$)	×	
		Bray, 2017	Scores reduced for befrienders ($P = 0.026$), no significant change for befriendeds ($P = 0.152$)	✓	
Stress	PSI-SF	Dababnah, 2016	Stress scores decreased ($P < 0.01$)	✓	Mixed findings. Five out of seven studies found reductions in parenting stress, four of which reported significant change
	PIP	Mills, 2021	Scores decreased ($P < 0.01$, $r = 0.34$)	✓	
	BFDS	Niinomi, 2016	Observed improvement, but the improvement in scores was not found to be significant	?	
		Blake, 2019	Improvement over time, analysed as one group ($t = 2.08$, $P = 0.048$)	✓	
		Borek, 2018	Improved well-being scores ($P < 0.05$)	✓	
		Martin, 2019	Parents' well-being improved ($d = 1.10$, $P < 0.001$)	✓	
		Mills, 2021	Improvement in ORS over time ($P < 0.01$)	✓	
		Martin, 2019	Parents' gratitude improved ($d = 0.90$, $P < 0.001$)	✓	
		Fung, 2018	Hope scores improved ($d = 1.02$, $P < 0.001$)	✓	
		Akre, 2015	AAQ-II scores improved ($P = 0.001$)	✓	
Well-being	SE-MCDS		No significant difference between scores for self-efficacy. Scores observed to worsen from T0 to T1 ($P = 0.79$) and then improve from T0 and T2 ($P = 0.15$)	×	The majority of studies showed a significant improvement in well-being for parent
	PSOC	Stuttard, 2016	Improvements in scores. PSOC-Sat $P = 0.004$, PSOC-Eff $P = 0.001$	✓	
	FCOPES	Akre, 2015	No significant difference between scores for coping. Scores observed to improve from T0 to T1 ($P = 0.31$) but worsen from T0 to T2 ($P = 0.51$)	×	
	RS-14	Blake, 2019	Analysed as one group, the scores were not statistically significant ($t = -1.65$, $P = 0.11$)	×	
	Footsteps Tool		Improvement over time, analysed as one group ($t = 2.08$, $P = 0.048$)	✓	
	WEMWBS		Improved well-being scores ($P < 0.05$)	✓	
	ORS		Parents' well-being improved ($d = 1.10$, $P < 0.001$)	✓	
	GD-6		Improvement in ORS over time ($P < 0.01$)	✓	
	AHS		Parents' gratitude improved ($d = 0.90$, $P < 0.001$)	✓	
	AAQ-II		Hope scores improved ($d = 1.02$, $P < 0.001$)	✓	
Elements of well-being			No significant difference between scores for self-efficacy. Scores observed to worsen from T0 to T1 ($P = 0.79$) and then improve from T0 and T2 ($P = 0.15$)	×	Mixed findings. Four out of seven studies showed significant improvement. Findings from three measures were not clear to show improvement in outcomes for parents
			Improvements in scores. PSOC-Sat $P = 0.004$, PSOC-Eff $P = 0.001$	✓	
			No significant difference between scores for coping. Scores observed to improve from T0 to T1 ($P = 0.31$) but worsen from T0 to T2 ($P = 0.51$)	×	
			Analysed as one group, the scores were not statistically significant ($t = -1.65$, $P = 0.11$)	×	
			Improvement over time, analysed as one group ($t = 2.08$, $P = 0.048$)	✓	
			Improved well-being scores ($P < 0.05$)	✓	
			Parents' well-being improved ($d = 1.10$, $P < 0.001$)	✓	
			Improvement in ORS over time ($P < 0.01$)	✓	
			Parents' gratitude improved ($d = 0.90$, $P < 0.001$)	✓	
			Hope scores improved ($d = 1.02$, $P < 0.001$)	✓	

TABLE 4 (Continued)

Themes	Measures	Author	Findings	Direction of effect	Summary of findings
QoL	Peds QL	Bray, 2017	Observed improvement however not a significant difference for both befriendees ($P = 0.11$) and befrienders ($P = 0.44$)	?	Significant improvement in QoL for parents/caregivers in three of five studies
	VLQ	Fung, 2018	Improvement in scores ($P = 0.001$)	✓	
	QLESQ-SF	Mills, 2021	Observed improvement in scores ($d = 0.21$, $P < 0.05$)	✓	
	WHO-QoL26	Niinomi, 2016	Scores showed improvement from intervention ($P < 0.05$)	✓	
	PROMIS	Wilford, 2020	Observed improvement favourable towards intervention (significance not reported)	?	

Note: '✓' indicates favourable towards (peer support) intervention ($P < 0.05$); '?' indicates observed or marginal benefit favouring (peer support) intervention group; 'x' indicates no difference between groups, effect favouring control group.

Abbreviations: AAQ-II, Acceptance and Action Questionnaire; AHS, Adult Hope Scale; BFDS, Brief Family Distress Scale; CFQ, Cognitive Fusion Questionnaire; DASS-21, Depression Anxiety Stress Scales; FCOPEs, Family Crisis Oriented Personal Evaluation Scale; GD-6, Gratitude Questionnaire-12; GHQ-12, General Health Questionnaire-12; HADS, Hospital Anxiety and Depression Scale; ORS, Outcome Rating Scale; Peds QL, Pediatric Quality of Life; PHQ-9, Patient Health Questionnaire-9; PIP, Pediatric Inventory for Parents - scale of parent stress level in frequency (PIP-F) and difficulty (PIP-D); PROMIS, Patient-Reported Outcomes Measurement Information System; PSI, Parenting Stress Index; PSI-SF, Dutch version of Parenting Stress Index Form; PSOC, Parenting Sense of Competence Scale; PSS, Parental Stress Scale; PS-SF, Parenting Stress - Short Form; QLESQ-SF, Quality of Life Enjoyment and Satisfaction Questionnaire - Short Form; RS-14, Resilience Scale - 14; SE-MCDS, Self-Efficacy for Managing Chronic Disease Scale; VLQ, Valued Living Questionnaire; WEMWBS, Warwick-Edinburgh Mental Well-being Scale; WHO-QoL26, World Health Organization - Quality of Life 26.

for parents and caregivers following the peer support programmes. However, the outcomes reported by Blake et al. (2019) should be interpreted with caution due to the high participant dropout rate.

Seven studies focused on factors that contribute to well-being, including gratitude, hope, resilience and competence, with mixed findings. Four measures from three studies (Fung et al., 2018; Martin et al., 2019; Stuttard et al., 2016) found significant improvement in scores for parents/caregivers, whereas the remaining three measures reported in the studies by Akre et al. (2015) and Blake et al. (2019) did not show significant outcomes or any difference in outcomes for parents. Positive findings were reported in outcomes that related to gratitude, hope, psychological flexibility and competence (Fung et al., 2018; Martin et al., 2019; Stuttard et al., 2016). Outcomes related to self-efficacy, coping and resilience in studies by Akre et al. (2015) and Blake et al. (2019) did not change significantly, although both studies had among the highest risk of bias of all the included studies.

3.4.3 | QoL

QoL outcomes were measured in five studies (Bray et al., 2017; Fung et al., 2018; Mills et al., 2021; Niinomi et al., 2016; Wilford et al., 2020). In these studies, parents/caregivers participated in a variety of programmes with a differing style and frequency of intervention. Three studies (Bray et al., 2017; Mills et al., 2021; Wilford et al., 2020) had a weekly intervention; one intervention was monthly (Niinomi et al., 2016), and the other (Fung et al., 2018) was a day programme. All five studies observed at least small improvements in measures of QoL associated with participation in peer support programmes, with three reaching statistical significance.

4 | DISCUSSION

This systematic review of 13 quantitative articles suggests that programmes for parents/carers of children with disability and/or chronic illness that involve a significant peer support component are associated with decreases in parental/carer distress and increases in well-being and QoL outcomes, with many of the studies finding significant improvements in the measures used. However, although these results are promising, all the studies included various degrees of bias, with compromised study quality. Notably, the review did not find any evidence that peer support programmes cause harm or negative effects, but the effectiveness and efficacy of such programmes remain uncertain.

Over a decade ago, Davies and Hall (2005) highlighted the benefits of peer support programmes for parents/carers of children with disability/chronic illness, in combination with accurate information and resources provided by professionals, to reduce isolation, improve confidence and increase parents'/carers' capacity to meet the needs of their child. Our review of findings in the past decade supports this assertion, further suggesting that peer support may help to reduce

distress and increase well-being and QoL of parents/carers and their families.

Our systematic review complements and extends on a previous review in this field (Shilling et al., 2013) by reporting on studies undertaken in the subsequent decade. Shilling et al. (2013) focused on studies published prior to 2011, whereas our review focused on quantitative studies published in the last decade. Shilling et al. (2013) identified four themes arising from qualitative evidence: benefits of finding social identity, learning from others, parents developed personal growth and the importance of supporting others. Our results further suggest that peer support programmes may result in measurable decreases in distress and increases in well-being and QoL. Although the findings of both reviews are promising, concerns remain regarding the quality of the included studies. Shilling et al. (2013) highlighted the low quality of reporting and analysis. The assessment of bias included in the current review indicated high risk of bias in one or more domains for all included studies, suggesting that research quality continues to be a limitation in this field of research.

The strengths of our review include the use of a systematic review methodology prospectively registered with PROSPERO, reporting according to the PRISMA statement and using the RoB 2 tool to assess risk of study bias. The RoB 2 tool used to assess the quality of the studies was designed for randomized controlled trials, however, and its appropriateness for the group of studies identified for inclusion in this review could be questioned. Nevertheless, the RoB 2 tool was able to differentiate risk of bias between the included studies, adding important guidance for specific ways to improve the quality of studies in the future.

Our review included studies across a range of modalities, with insufficient studies available to differentiate characteristics that are necessary or sufficient. The provision of peer support needed, including how often and for how long, is unclear. The interventions in the programmes in this review varied from weeks to months, and the frequency of contact between parents/caregivers and peer supports also varied. For example, in one study (Fung et al., 2018), participants had a 1.5-day group intervention with a follow-up, and in another study (Dababnah & Parish, 2016), participants completed a 2-h weekly session for 15 weeks. For most of the studies, participants completed six to eight sessions (1- to 2-h duration) of the intervention programme held weekly or fortnightly. The frequency of peer support sessions did not clearly align with any specific outcomes. Therefore, studies are needed to understand what types of peer support are most beneficial, as well as the benefits and weaknesses of different modalities, mediums, frequency and duration. These are especially important questions to consider with limited time available to parents/carers for participation in such programmes and the costs and resources involved in delivering such programmes. Further consideration of costs and benefits will be important for peer support elements to become a policy and standard care.

Our review had several limitations. It is possible that the included studies did not capture the most vulnerable parents/caregivers, as they reported on interventions for parents/carers who had the capacity to participate in a group programme. All the

studies were from English-speaking countries; this may be partially explained by the requirement that papers be written in English (a pragmatic decision based on resourcing and a possible limitation of the study) but may also reflect a degree of publication bias or a difference in the prevalence of peer support programmes in different cultural settings. Although assessments were included, not all participants completed measures, and this may have resulted in biased reporting in the original studies, which subsequently became a part of the systematic reviews. Most of the studies had pre-designs–post-designs with a single sample, making it unclear whether changes occurred due to the programme, placebo effects or other unmeasured factors. Causality cannot be determined nor are conclusions definitive. In addition, for many of the studies, peer support was often delivered as part of a bundle of interventions. It is not certain that the element of peer support was the factor that improved outcomes for parents/carers. Peer support is complex and consists of many components that contribute to a person's well-being, QoL and ability to support their child. More rigorous research designs with low risk of bias are required to gain a better understanding of the benefits peer support may have for parents and provide greater confidence in the body of evidence.

5 | CONCLUSION

Our findings from a review of 13 quantitative articles suggest that group support programmes for parents/carers of a child with disability or chronic illness that contain a significant peer support component aid in reducing distress and improving well-being and QoL for participants. Although the lack of rigour and potential bias in the studies make our findings far from conclusive, no studies found negative impacts. As a whole, peer support appears to be a promising approach for proactively supporting parents and carers, contributing to the vision of improving life for families from all backgrounds despite the challenges that disability and illness bring.

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CONFLICTS OF INTEREST

The authors report no conflicts of interest.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

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