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REVIEW ARTICLE

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The effectiveness of interventions to improve psychosocial outcomes in parents of children with appearance-affecting health conditions: A systematic review

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Abstract

Background: Although many cope well, the impact of supporting a child with an Appearance-Affecting Health Condition (AAHC) can place a significant demand on parents. As such, it is vital that families have access to appropriate psychosocial support to reduce any potential difficulties. Although previous reviews have explored the effectiveness of psychosocial interventions for parents of Children and Young People (CYP) with general health conditions, the evidence of effectiveness remains limited. Further, little is known about the effectiveness of such interventions specifically among parents of CYP with AAHCs. This review aimed to identify and assess the evidence of effectiveness of psychosocial interventions among parents of CYP with AAHCs.

Methods: Database searches were conducted using MEDLINE, PsychARTICLES, PsychINFO, CINAHL Plus, the British Nursing Database and the Cochrane Library. Results were reviewed against the inclusion criteria and data were extracted. Methodological quality was assessed using the Effective Public Health Practice Project Quality Assessment Tool, and a narrative synthesis was conducted.

Results: Fifteen studies, evaluating 10 interventions, were included and overall seven interventions were found to be effective (effect sizes and methodological quality varied).

Conclusions: This review finds moderate to strong evidence of effectiveness of the Triple P Positive Parenting Program, the Early Family Intervention Program and general parent education/training interventions. These findings offer useful insights relating to the delivery of current support, as well as for the development of future parent and family interventions. Finally, recommendations for future intervention evaluation studies in this area are made.

KEYWORDS
appearance, health, interventions, parents, systematic review, visible difference

1 | INTRODUCTION

Research suggests that parents of Children and Young People (CYP; defined here as <18 years) with a variety of health conditions may be at risk of experiencing psychosocial difficulties, including stress and post-traumatic stress, anxiety, depression, social isolation, problems with familial relations, sleep disturbance and overall reduced quality of life (QoL) (Ablett & Thompson, 2016; Bakker, Van der Heijden, Van Son, & Van Loey, 2013; De Young, Hendrikz, Kenardy, Cobham, & Kimble, 2014; Fawcett, Baggaley, Wu, Whyte, & Martinson, 2005; Moore, David, Murray, Child, & Arkwright, 2006). Such difficulties are likely to be a result of the challenges brought about from parenting a child with health demands (Basra, Sue-Ho, & Finlay, 2007; Cousino & Hazen, 2013; Dewey & Crawford, 2007; Holm, Patterson, Rueter, & Wamboldt, 2008; Horridge, Cohen, & Gaskell, 2010; McGarry et al., 2015). Given that these parents experience such a plethora of challenges, it is not surprising that their own wellbeing is often compromised.

A visible difference relates to an appearance that is notably different to the 'norm' and can result from a range of issues, including skin or congenitial conditions, scarring, or medical treatments (Rumsey & Harcourt, 2004). Having a visible difference, or Appearance-Affecting Health Condition (AHHC) presents unique challenges for CYP (Holmbeck, 2002; Rumsey & Harcourt, 2007; Strauss et al., 2007), and parents of CYP with AHHCs may therefore be at risk of additional trials to those already discussed above (Basra et al., 2007; Hlongwa & Rispel, 2018; Klein, Pope, Getahun, & Thompson, 2006; Nelson, Glenny, Kirk, & Caress, 2012; Nidey, Moreno Uribe, Marazita, & Wehby, 2015). Such trials are likely related to parents having to navigate issues around the social impact (and stigma) of their child looking different; managing other people's attitudes and reactions, as well as incidents of teasing, bullying and social exclusion. Parents might also experience anxiety related to decision-making about elective treatments to correct their child's appearance. As such, parents of CYP with AAHCs likely experience the same challenges as parents of CYP with general health conditions, as well as additional and nuance challenges associated with their child looking different.

Importantly, research finds that parents play a unique and integral role in their child's health and wellbeing, and that parental psychological distress is a key risk factor for poor medical and psychosocial outcomes in CYP (El Hamaoui, Yaalaoui, Chihabeddine, Boukind, & Moussaoui, 2006; Heath, Williamson, Williams, & Harcourt, 2019; Helgeson, Becker, Escobar, & Siminerio, 2012; Klinnert, Kaugars, Strand, & Silveira, 2008; Noronha & Faust, 2007). Thus, it is important that parents have access to appropriate support to ensure they are equipped to care for and support their child in the most optimal way (Ablett & Thompson, 2016; El Hamaoui et al., 2006; Hall et al., 2005; Heath et al., 2019; Nelson, Caress, Glenny, & Kirk, 2012; Phillips, Fussell, & Rumsey, 2007; Rumsey & Harcourt, 2007). However in practice, psychosocial family support of this kind is often limited and/or inadequate (Morawska, Sanders, Haslam, Filus, & Fletcher, 2014). In recognition of the issues discussed above, researchers and clinicians in this area are working to increase -the amount of evidence-based support available. For example, Heath and colleagues (2019) developed a website to support parents of burn-injured children (www.supportingchildrenwithburns.co.uk). The website includes psychosocial intervention content related to 'dealing with the reactions of others', 'responding to other people's questions', 'bullying' as well as other support/information to help parents adapt to and cope with their child's altered appearance.

In light of these issues, previous systematic reviews have assessed the evidence of effectiveness of psychosocial interventions for parents of CYP with general health conditions (Eccleston, Fisher, Law, Bartlett, & Palermo, 2015; Eccleston, Palermo, Fisher, & Law, 2012; Law, Fisher, Eccleston, & Palermo, 2019). These reviews have found some evidence that Problem Solving Therapy (PST) and Cognitive Behavioural Therapy (CBT) can be effective for improving parenting behaviour and that PST can be effective for improving parent mental health. However, the authors of these reviews stress that the quality of evidence is generally low, and as such, the evidence of effectiveness of these types of interventions remains limited. Furthermore, there is currently no systematic review evaluating these interventions specifically among parents of CYP with AAHCs. A comprehensive understanding of the current state of evidence in this field would be useful to inform the development and evaluation of future evidenced-based interventions tailored to this specific group's needs. The objective of this review is therefore to identify and

Key messages

- Parents of Children and Young People (CYP) with Appearance-Affecting Health Conditions (AAHCs) can experience a number of unique challenges pertaining to their child having a health need and looking different. Support for this parent group is necessary yet at present limited. This is the first systematic review to evaluate the effectiveness of psychosocial interventions specifically among parents of CYP with AAHCs.
- The review finds mixed evidence for the effectiveness of the Triple P Positive Parenting Program, the Early Family Intervention Program and general educational interventions. These findings may be useful for those working towards adapting existing or designing new interventions for this parent group.
- Methodological quality of evaluation studies is mixed, with lack of blinding being a key issue. The authors stress the need for more rigorous methodology in this area. The authors also make a number of other recommendations for future research, including the need for more diverse samples, mixed-methods approaches to determine intervention acceptability, as well as evaluation of intervention cost-effectiveness.

critically evaluate the evidence-base of existing psychosocial interventions among parents of CYP with AAHCs.

2 | METHOD

This systematic review was conducted in compliance with the Cochrane handbook for Systematic Reviews and reporting followed the PRISMA statement (Moher, Liberati, Tetzlaff, Altman, & Group, 2009; The Cochrane Collaboration,). A protocol is available on request. PROSPERO registration: CRD42019119959.

2.1 | Search strategy

Searches were conducted in January 2019 using the following databases: MEDLINE, PsychARTICLES, PsychINFO, CINAHL Plus, the British Nursing Database and the Cochrane Library. A combination of intervention and population terms were used in the searches (a full list of search terms is available in supporting information). To reduce risk of publication bias (Rosenthal, 1979), a grey literature search was also conducted. Further, experts in the field were contacted to discuss potential published or unpublished studies that they might have been aware of. Finally, relevant journals were hand searched (e.g., *Body Image*, *Journal of Pediatric Psychology* and *Child: Care, Health and Development*), and the reference lists of all included articles and relevant previous reviews (Eccleston et al., 2015, 2012; Law et al., 2019) were examined.

2.2 | Eligibility criteria

To be included in this review, articles had to be in English. No time limits were applied on the age of the study. Literature reviews, case studies, dissertations/theses and meta-analyses were excluded. Additionally, the following PICO criteria was adhered to:

- Population: Studies had to include parents and/or guardians of CYP (<18 years) with AAHCs (congenital or acquired). Studies had to have been conducted in high-income or upper-middle income countries (World Bank, 2017) to ensure relevance to Western healthcare systems.
- Intervention: Studies had to involve a psychosocial intervention.
- Comparison: Studies had to make a comparison between an intervention group and a control group.
- Outcome: Studies had to include at least one quantitative psychosocial (primary or secondary) outcome measure which had to be assessed pre- and post-intervention. Post-test only studies were excluded. Mixed-method studies were included (although only

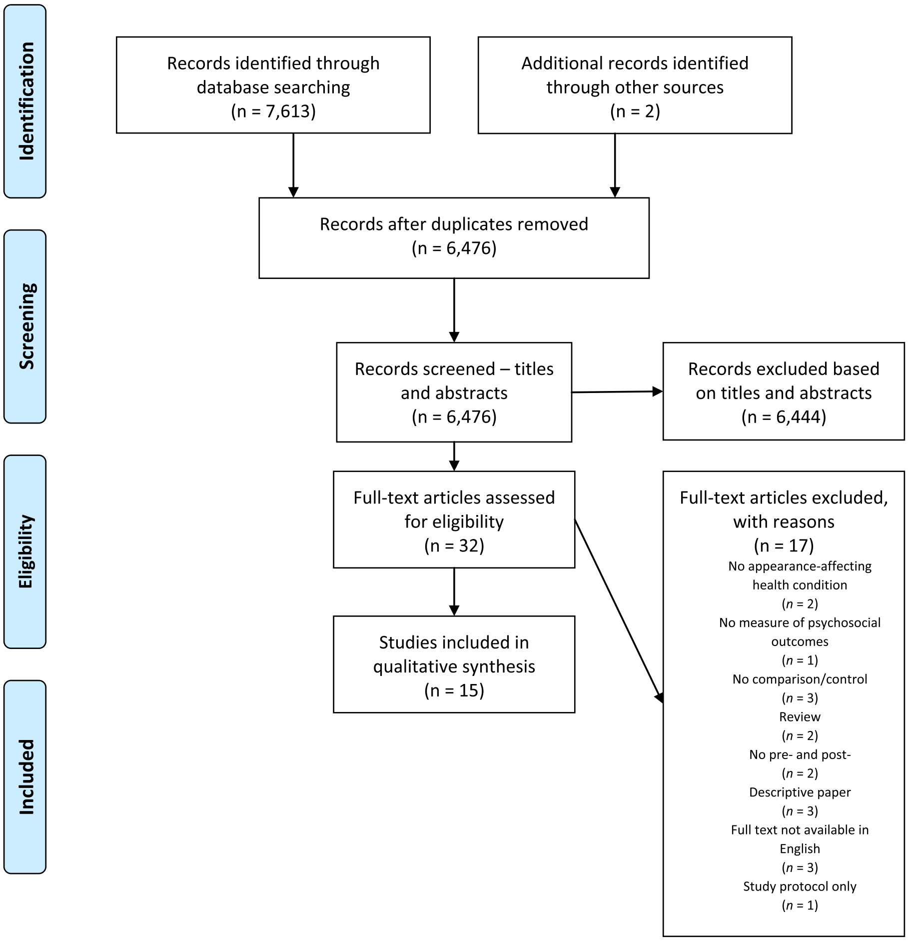

FIGURE 1 PRISMA flow diagram [Colour figure can be viewed at wileyonlinelibrary.com]

TABLE 1 Characteristics and results of studies

Study characteristics				Sample characteristics		Conditions		Results
Study and location	**Design**	**Condition**	**Target population**	**Sample size**	**Measurement time(s)**	**Intervention**	**Control**	**Findings (*p* values shown for significant results and effect sizes[a] (*d*) where possible)**
Chinn et al., 2002, Teeside, UK	RCT	Atopic eczema (AE)	Children (6 months to 16 years) with AE and their families	235 (119 in intervention and 116 in control)	Baseline, 4 weeks, 12 weeks	Single consultation with nurse	Not described (ND)	No significant reduction of impact on family
Futamura et al., 2013, Aichi, Japan	RCT	Atopic dermatitis (AD)	Children (6 months to 6 years) with moderate to severe AD and their parents	59 (29 in intervention and 30 in control)	Baseline, 3 months, 6 months	Parental education program (PEP)	Care as usual (CAU).	1.No significant DFI score improvement 2.Significant improvements in parent anxiety related to CS use in intervention group at 3 ($p = 0.02$) and 6 ($p = 0.02$) months compared with control group
Grillo et al., 2006 Adelaide, Australia	RCT	AE	Patients (0 to 16 years) diagnosed with (nonsevere) AE and their parents	61 (29 in intervention and 32 in control)	Baseline, 4 weeks, 12 weeks	PEP	Wait control (WC)	No significant DFI score improvement in intervention group
Hemati, Abbasi, Oujian, & Kiani, 2017, Isfahan, Iran	Quasi	Cleft lip and palate (CLP)	Mothers of children (0 to 12 years) with CLP	64 (unclear about numbers per condition)	Baseline, 2 months	Fordyce Happiness Program	ND	Intervention group mothers showed better performance compared with control across all FPQ domains (*p* values ranging from 0.02 to 0.000) as well as overall performance ($p < 0.0000$, $d = 1.262$)
Hemati, Abbasi, Paki, & Kiani, 2017, Isfahan, Iran	Quasi	CLP	Mothers of children (0 to 12 years) with CLP	64 (unclear about numbers per condition)	Baseline, 2 months	Fordyce Happiness Program	ND	Intervention group mothers reported less perceived stress than control group after intervention ($p = 0.007$, $d = 0.695$)
Kupfer et al., 2010, Berlin, Germany	RCT	AD	Parents of children with AD	206 (105 in intervention and 101 in control)	Baseline, 12 months	PEP	WC	Significant improvement in intervention group

TABLE 1 (Continued)

Study characteristics				Sample characteristics		Conditions		Results
Study and location	Design	Condition	Target population	Sample size	Measurement time(s)	Intervention	Control	Findings (*p* values shown for significant results and effect sizes[a] (*d*) where possible)
								compared with control in three-fourth subscales (*p* values ranging from 0.002 to 0.003, *d* values ranging from 0.105 to 0.207)
Morawska, Mitchell, Burgess, and Fraser (2016), Brisbane, Australia	RCT	Eczema	Parents of children (2 to 12 years old) with eczema	107 (52 in intervention and 55 in control)	Baseline, post-intervention and 6 months	Triple P positive parenting program (PPP)	CAU	1.PASECI - intervention group parents showed greater improvements compared with control group ($p = 0.01$, $d = 0.54$) 2.EBC - intervention group parents showed greater improvements compared with control group ($p = 0.001$, $d = 0.64$) 3.PQL – intervention group showed greater improvement in both parent QoL ($p = 0.009$, $d = 0.23$) and family QoL ($p = 0.01$, $d = 0.08$) compared with control group
Morawska, Mitchell, Burgess, and Fraser (2017a), Brisbane, Australia	RCT	Eczema	Parents of children (2 to 12 years old) with eczema	107 (52 in intervention and 55 in control)	Baseline, post-intervention and 6 months	PPP	CAU	1.PS – significant improvement in over-reactivity ($p = 0.015$, $d = 0.47$) and total ($p = 0.006$, $d = 0.66$) scores for intervention group

(Continues)

TABLE 1 (Continued)

Study characteristics				Sample characteristics		Conditions		Results
Study and location	**Design**	**Condition**	**Target population**	**Sample size**	**Measurement time(s)**	**Intervention**	**Control**	**Findings (*p* values shown for significant results and effect sizes[a] (*d*) where possible)**
								compared with control. No significant improvement in laxness for intervention group 2.CAPES – no significant improvement for intervention group 3.DAS – significant improvement in stress levels for intervention group compared with control ($p = 0.023$, $d = 0.20$). No significant improvement in anxiety or depression levels for intervention group
Morawska, Mitchell, Burgess, and Fraser (2017b), Brisbane, Australia	RCT	Eczema	Fathers of children (2 to 12 years old) with eczema	55 (31 in intervention and 24 in control)	Baseline, post-intervention and 6 months	PPP	CAU	1.PASECI - intervention group showed greater improvements ($p = 0.001$, $d = 0.66$) compared with control group 2.No significant improvements in EBC or PQL-FIM in intervention group compared with control

TABLE 1 (Continued)

Study characteristics				Sample characteristics		Conditions		Results
Study and location	Design	Condition	Target population	Sample size	Measurement time(s)	Intervention	Control	Findings (p values shown for significant results and effect sizes[a] (d) where possible)
Pelchat et al., 1999, Quebec and Montreal, Canada	Quasi	CLP	Parents (couples only) of children with CLP	43 families (16 families in intervention group and 27 families in control group)	When child was 6, 12 and 18 months old	Early family intervention program	CAU	1.SAM – intervention parents were less threatened ($p < 0.05$, $d = 0.309$) and more confident ($p < 0.01$, $d = 0.611$) compared with control group 2.EDI – intervention parents reported less emotional distress, anxiety and depression ($p < 0.05$) compared with control group ($d = 0.517, 0.553, 0.472$) 3.Spousal support – intervention parents perceived more spousal emotional support ($p < 0.05$, $d = 0.416$) compared with control group
Pustisek et al., 2016, Zagreb, Croatia	RCT	AD	Parents of children (aged 3 months to 7 years) with moderate–severe AD	134 (66 in intervention and 68 in control)	Baseline and 2 months	PEP	CAU	4.PSS – intervention group had significantly lower levels of perceived stress ($p = 0.024$, $d = 0.403$) compared with control 5.STAI – intervention group had significantly lower levels of state (but not trait) anxiety ($p = 0.042$, $d = 0.364$) compared with control

(Continues)

TABLE 1 (Continued)

Study characteristics				Sample characteristics		Conditions		Results
Study and location	Design	Condition	Target population	Sample size	Measurement time(s)	Intervention	Control	Findings (*p* values shown for significant results and effect sizes[a] (*d*) where possible)
								6.FDLQI – intervention group reported lower total impact ($p = 0.006$, $d = 0.497$) as well as lower impact on emotional distress ($p = 0.000$), physical well-being ($p = 0.001$) and time spent looking after chid ($p = 0.005$) compared with control
Santer et al., 2014, Berkshire, UK	RCT	Eczema	Parents of children (<5 years) with GP diagnosis of eczema	148 (51 in control, 46 in web only intervention and 51 in web and healthcare professional (HCP) intervention)	Baseline and 12 weeks	Intervention 1 - Web-based support only (SPaCE = Supporting Parents and Carers of Children with Eczema)-Intervention 2 - Web-based and HCP support (single appointment)	CAU	Baseline scores were too low to demonstrate differences (floor effects)
Staab et al., 2002, Berlin, Germany	RCT	AD	Parents of children with AD	204 (93 in intervention and 111 in control)	Baseline and 1 year	PEP	WC	1.Disease-specific QoL – greater increase in intervention group regarding confidence in medical treatment compared with control ($p = 0.016$)

TABLE 1 (Continued)

Study characteristics				Sample characteristics		Conditions		Results
Study and location	Design	Condition	Target population	Sample size	Measurement time(s)	Intervention	Control	Findings (*p* values shown for significant results and effect sizes[a] (*d*) where possible)
								2.TSC – at 1 year follow up, there was a greater decrease in rumination in intervention group compared with control ($p = 0.013$)
Staab et al., 2006, Berlin, Germany	RCT	AD	Young people with AD and their parents	992 (498 in intervention and 496 in control)	Baseline and 1 year	PEP	CAU	1.Improvement in QoL for parents of children aged 3–7 years was significantly greater in intervention group compared with control for all 5 subscales (*p* values range from <0.001 to 0.004; *d* values range from 0.399 to 0.569) 2.Improvement in QoL for parents of children aged 8–12 years was significantly greater in intervention group compared with control for 3 subscales (confidence in medical treatment, emotional coping and acceptance of disease; *p* values range from <0.001 and 0.031; *d* values range from 0.241 to 0.676)

(Continues)

TABLE 1 (Continued)

Study characteristics				Sample characteristics		Conditions		Results
Study and location	**Design**	**Condition**	**Target population**	**Sample size**	**Measurement time(s)**	**Intervention**	**Control**	**Findings (*p* values shown for significant results and effect sizes[a] (*d*) where possible)**
Sveen et al., 2017, Uppsala, Sweden	RCT	Burns	Parents of children (<18 years) with burns	105 parents (52 in control and 52 in intervention)	Baseline (T1), 6 weeks (T2), 3 months (T3) and 12 months (T4)	Web intervention	WC	1.IES-R – intervention group had improved scores at T2 ($p = 0.003$, $d = 0.617$) and T3 ($p = 0.020$. $d = 0.466$) in comparison with control group 2.No intervention effects on all other outcomes

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[a] Effect sizes (Cohen's *d*) were manually calculated by the authors where possible by calculating the mean difference between the two groups and then dividing the result by the pooled standard deviation. Some effect sizes could not be calculated as the authors of the original paper did not provide means and/or standard deviations. Effect sizes were not manually calculated for Morawska et al. (2016, 2017a & 2017b) as the authors already provided Cohen's *d* (calculated by pre-post change in intervention group minus pre-post chance in control group, divided by the pooled baseline standard deviation for each measure).

quantitative findings were extracted). Qualitative-only method studies were excluded.

Titles and abstracts were reviewed against thes eligibility criteria. Full texts were reviewed by the first and second author. Any discrepancies were discussed and resolved by consensus. The data screening process is presented in a PRISMA flow diagram (see Figure 1).

2.3 | Data extraction

Following guidelines from the Cochrane Handbook for Systematic Reviews (Higgins & Green, 2011), data extraction was conducted independently by the first and second author. Any discrepancies were discussed and resolved by consensus. All extracted data are presented in Table 1. Further details pertaining to outcome measures and intervention content can be found in supporting information.

2.4 | Methodological quality assessment

Methodological quality assessment for the included studies was carried out by the first and third author using the Quality Assessment Tool for Quantitative Studies, developed by the Effective Public Health Practice Project (EPHPP; Thomas, Ciliska, Dobbins, & Micucci, 2004). In accordance with the EPHPP, each study was judged to be 'strong', 'moderate' or 'weak', based on factors including selection bias, study design, confounders, blinding, data collection method and withdrawals/dropouts (see Table 2).

2.5 | Appraisal of intervention effectiveness

Interventions were considered effective if there was a statistically significant improvement in psychosocial outcome(s) in the intervention group compared with the control group. Further, in order to quantify the differences between the intervention and control groups, effect sizes were calculated where possible (see Table 1). Effect sizes were interpreted as follows: small $d = 0.2$, medium $d = 0.5$, large $d = 0.8$ (Rosenthal & Rosnow, 1996).

3 | RESULTS

Following screening and assessment of eligibility, 15 studies, evaluating 10 interventions, were included in this review. Included studies varied in design, intervention approach and outcome measures; therefore, a meta-analysis was not appropriate (Liberati et al., 2009), and findings were synthesized narratively. The following narrative synthesis begins by describing study characteristics, samples, parent outcomes and methodological quality. Then, the evidence of effectiveness is examined according to type of intervention, with a reference to methodological quality throughout to frame study

TABLE 2 Methodological quality assessment using Effective Public Health Practice Project (EPHPP) tool

Study	Selection bias	Study design	Confounders	Blinding	Data collection method	Withdrawals and dropouts	Global quality rating
Futamura et al. (2013)	2	1	1	2	1	1	Strong
Grillo et al. (2006)	2	1	1	2	1	1	Strong
Kupfer et al. (2010)	1	1	1	2	1	1	Strong
Morawska et al. (2017a)	2	1	1	3	1	1	Moderate
Morawska et al. (2017b)	2	1	1	3	1	1	Moderate
Pelchat et al. (1999)	1	1	1	3	1	2	Moderate
Staab et al. (2002)	1	1	1	3	1	2	Moderate
Chinn et al. (2002)	3	1	1	3	1	2	Weak
Hemati, Abbasi, Paki, Oujian, & Kiani, (2016)	2	1	1	3	1	3	Weak
Hemati, Abbasi, Oujian, & Kiani (2017)	2	1	1	3	1	3	Weak
Morawska et al. (2017b)	2	1	3	3	1	2	Weak
Pustisek et al. (2016)	2	1	3	3	1	1	Weak
Santer et al. (2014)	3	1	3	3	1	1	Weak
Staab et al. (2006)	3	1	1	3	1	2	Weak
Sveen et al. (2017)	3	1	1	3	1	2	Weak

Quality ratings: 1 = Strong, 2 = Moderate, 3 = Weak.

findings. Note that although some results may be from the same study or sample, they are published in separate papers and are thus treated independently in this review.

3.1 | Study characteristics

Included studies were published within the past 18 years (1999–2017) and were carried out in a range of countries; two in the United Kingdom (Chinn, Poyner, & Sibley, 2002; Santer et al., 2014), one in Japan (Futamura, Masuko, Hayashi, Ohya, & Ito, 2013), four in Australia (Grillo, Gassner, Marshman, Dunn, & Hudson, 2006; Morawska et al. 2016; Morawska et al. 2017a; Morawska et al. 2017b), two in Iran (Hemati, Abbasi, Oujian, & Kiani, 2017; Hemati, Abbasi, Paki, & Kiani, 2017), three in Germany (Kupfer et al., 2010; Staab et al., 2006, 2002), one in Canada (Pelchat, Bisson, Ricard, Perreault, & Bouchard, 1999), one in Croatia (Pustisek et al., 2016) and one in Sweden (Sveen, Andersson, Buhrman, Sjoberg, & Willebrand, 2017). Most studies were randomised controlled trials (RCT; Chinn et al. 2002; Futamura et al.; Grillo et al., 2006; Kupfer et al., 2010; Morawska et al., 2016, 2017a & 2017b; Pustisek et al., 2016; Santer et al., 2014; Staab et al., 2002 & 2006; Sveen et al., 2017); however, three were quasi-experimental studies owing to a lack of random condition assignment (Hemati, Abbasi, Oujian, & Kiani, 2017;Hemati, Abbasi, Paki, & Kiani, 2017; Pelchat et al., 1999). Studies explored a number of AAHCs; six focused on atopic eczema (Chinn et al., 2002; Grillo et al., 2006; Morawska et al., 2016, 2017a & 2017b; Santer et al., 2014), five on atopic dermatitis (Futamura et al., 2013; Kupfer et al., 2010; Pustisek et al., 2016; Staab et al., 2002 & 2006), three on cleft lip and/or palate (Hemati, Abbasi, Oujian, & Kiani, 2017; Hemati, Abbasi, Paki, & Kiani, 2017; Pelchat et al., 1999) and one on burn injuries (Sveen et al., 2017).

3.2 | Sample characteristics

Across the 15 studies, 2,584 parents took part (1,239 were in intervention groups, although some studies did not report numbers per condition) and sample sizes ranged considerably (n = 43–992, m = 172). Most studies did not report parent demographic information and those that did reported different characteristics. Where reported, the mean age of parents ranged from 29.5 to 40.0, and parents were mostly White mothers (with the exception of Morawska et al., 2017b, who's sample consisted of only fathers).

3.3 | Assessment of psychosocial outcome(s)

Included studies assessed a number of parent psychosocial outcomes including family impact (Chinn et al., 2002; Futamura et al., 2013; Grillo et al., 2006; Santer et al., 2014), QoL (Morawska et al., 2016 & 2017b; Pustisek et al., 2016; Staab et al., 2002 & 2006), family function (Sveen et al., 2017; Hemati, Abbasi, Oujian, & Kiani, 2017), stress (Hemati, Abbasi, Paki, & Kiani, 2017; Pustisek et al., 2016; Sveen et al., 2017; Pelchat et al., 1999), post-traumatic stress (Sveen et al., 2017), self-efficacy (Morawska et al., 2016, 2017a & 2017b), parenting behaviour and discipline styles (Morawska et al., 2017a), emotional distress including depression and anxiety

(Morawska et al., 2017a; Pelchat et al., 1999; Pustisek et al., 2016; Sveen et al., 2017; Futamura et al., 2013), coping (Staab et al., 2002; Kupfer et al., 2010) and spousal support (Pelchat et al., 1999). These factors were assessed using a total of 27 measures; 21 validated and 6 non-validated (including measures adapted/developed by the authors). See supporting information for further details about outcome measures.

3.4 | Methodological quality of studies

A methodological quality assessment was carried out using the EPHPP tool by the first and third authors. Three studies were rated as strong (Futamura et al., 2013; Grillo et al., 2006; Kupfer et al., 2010), four as moderate (Morawska et al., 2016 & 2017a; Pelchat et al., 1999; Staab et al., 2006) and eight as weak (Chinn et al., 2002; Hemati, Abbasi, Oujian, & Kiani, 2017; Hemati, Abbasi, Paki, & Kiani, 2017; Morawska et al., 2017b; Pustisek et al., 2016; Santer et al., 2014; Staab et al., 2002; Sveen et al., 2017). All studies received a strong rating for study design and data collection methods; however, lack of blinding was a limitation of all studies. The three strong studies received a moderate rating for blinding (researchers or participants were blind or blinding was not described), but all other studies received weak ratings (researchers and participants were not blind).

3.5 | Effectiveness of interventions

Of the 15 studies included in this review, 12 studies testing seven interventions found some intervention effects. The following section of the review explores the evidence of effectiveness of these seven interventions according to type of intervention.

3.5.1 | Fordyce Happiness Program

Two weak studies (Hemati, Abbasi, Oujian, & Kiani, 2017; Hemati, Abbasi, Paki, & Kiani, 2017) tested the effectiveness of the Fordyce Happiness Program; a programme is designed to help people adopt a more positive attitude (Narrmashiri, Raghibi, & Mazaheri, 2015; Rabiei, Mazaheri, Masoudi, & Hasheminia, 2014). Hemati, Abbasi, Oujian and Kiani (2017) found significantly greater improvements in the overall performance of mothers in the intervention group with a very strong effect size ($p = 0.000$, $d = 1.262$). Hemati, Abbasi, Paki and Kiani (2017) found significantly greater improvements in the perceived stress of mothers in the intervention group with a medium effect size ($p = 0.007$, $d = 0.695$). Although these two studies found the Fordyce Happiness Program to be effective at improving performance and reducing perceived stress in mothers, both were rated as weak in terms of methodological quality (owing to issues with blinding and withdrawals/droup-outs), and as such findings should be interpreted with caution.

3.5.2 | Triple P Positive Parenting Program

Two moderate studies (Morawska et al., 2016, 2017a) and one weak study (Morawska et al., 2017b) tested the effectiveness of the Triple P Positive Parenting Program. The program is designed for parents of children (aged 2–12 years old) with chronic health conditions and aims to increase parenting confidence (Sanders, 2012). Morawska et al. (2016) found significantly greater improvements in the intervention group in relation to parents' self-efficacy for managing their child's condition ($p = 0.01$, $d = 0.54$), parents' confidence for managing their child's condition-related behavioural problems ($p = 0.001$, $d = 0.64$), as well as parent ($p = 0.009$, $d = 0.23$) and family ($p = 0.01$, $d = 0.08$) QoL. Effect sizes were small to medium. Similarly, Morawska et al. (2017a) found significantly greater improvements in the intervention group in relation parenting style ($p = 0.006$ and 0.015, $d = 0.47$ and 0.66) and stress ($p = 0.23$, $d = 0.20$). Effect sizes were small to medium. Morawska et al. (2017b) found significantly greater improvements in the intervention group in relation to parents' self-efficacy for managing their child's condition, with a medium effect size ($p = 0.001$, $d = 0.66$). These findings demonstrate moderate evidence for the effectiveness of the Triple P Positive Parenting Program for improving parent self-efficacy and confidence for managing their child's condition and condition-related behavioural problems, improving parent and family QoL, improving parenting style and reducing parental stress.

3.5.3 | Early Family Intervention Program

Pelchat's (1990) study of moderate quality tested the effectiveness of the Early Family Intervention Program; an intervention aiming to support parents adapt to having a child with a disability. Pelchat found significantly greater improvements in the intervention group in terms of reduced threat ($p = <0.05$, $d = 0.309$), increased confidence ($p = <0.01$, $d = 0.611$) and perceived spousal emotional support ($p = <0.05$, $d = 0.416$), as well as reduced emotional distress, anxiety and depression ($p = <0.05$, $d = 0.517$, 0.553 and 0.472). Effect sizes were small to medium. Pelchat's study demonstrates moderate evidence for the effectiveness of the Early Family Intervention Program for reducing perceived threat (by parental situation); increasing confidence (to receive help from others); increasing perceived spousal emotional support and reducing emotional distress, anxiety and depression among parents.

3.5.4 | Web interventions

Two studies of weak quality tested the effectiveness of web-based interventions (Santer et al., 2014; Sveen et al., 2017); however, only one by (Sveen et al.) found any intervention effects. Sveen and colleagues tested a website, aimed at supporting parents of CYP with burns. They found significantly greater improvements in post-traumatic stress in the intervention group at time two (p = 0.003, d = 0.617) and time three (p = 0.020, d = 0.466), with medium effect sizes. Although these findings suggest that this web-based intervention may be effective at improving post-traumatic stress in parents, the study was rated as weak in terms of methodological quality, and as such findings should be interpreted with caution.

3.5.5 | Parent training and education

Seven studies described their chosen intervention as parent training or education (Chinn et al., 2002; Grillo et al., 2006; Futamura et al., 2013; Kupfer et al., 2010; Pustisek et al., 2016; Staab et al., 2002 & 2006); however, only five found any intervention effects (Futamura et al., 2013; Kupfer et al., 2010; Pustisek et al., 2016; Staab et al., 2002 & 2006). In a strong study, Futamura et al. found significantly greater improvements in anxiety related to the use of corticosteroids (CS) in the intervention group at 3 and 6 months (p = 0.02). However, effect sizes could not be calculated. In a weak study, Pustisek et al. found significantly greater improvements in perceived stress (p = 0.024, d = 0.403), state anxiety (p = 0.042; d = 0.364) and overall family impact (p = 0.006, d = 0.497) in the intervention group. Effect sizes were small to medium. Kupfer et al. (2010) and Staab et al. (2002 & 2006) tested the same intervention. Kupfer et al.'s strong study found significantly greater improvements in three out of four coping subscales in the intervention group with small effect sizes (p = 0.002–0.003, d = 0.105–0.207). Staab et al.'s (2006) moderate study found significantly greater improvements in the intervention group in relation to QoL in parents of children aged three to seven across all subscales (p = 0.002–0.004, d = 0.399–0.569), as well as QoL in parents of children aged eight to 12 across three subscales (p = 0.001–0.031, d = 0.241–0.676). Effect sizes were small to medium. Finally, in Staab et al.'s (2002) weak study, significantly greater improvements in parent QoL (p = 0.016) and disease rumination (p = 0.013) were found at 1-year follow-up in the intervention group; however, effect sizes could not be calculated. Due to differences in study design and methodological quality, it is difficult to draw firm conclusions regarding the effectiveness of parent education interventions. However, there is strong evidence of the effectiveness of parent education for improving parental anxiety in relation to caring for their child as well as parental coping. There is also moderate evidence for the effectiveness of parent education for improving parent QoL.

4 | DISCUSSION

4.1 | Summary of findings

Parents of CYP with AAHCs can experience of number of psychosocial difficulties that have the potential to be ameliorated by psychosocial intervention. However, existing evidence of effectiveness is limited. Further, to the best of the authors' knowledge, this is the first systematic review to examine the evidence of effectiveness of psychosocial interventions among this specific parent group. Fifteen studies, evaluating 10 interventions, were included in this review. Of these, seven interventions tested in 12 studies were found to be effective.

The authors attempted to determine the most effective type of intervention for parents of CYP with AAHCs. Included studies varied greatly in terms of type of intervention; there were studies evaluating established programmes with strong theoretical underpinnings (Fordyce Happiness Program, Triple P Positive Parenting Program and Early Family Intervention Program), web-based interventions, as well as general parent education programs.

Overall, the current review finds moderate evidence for the effectiveness of the Triple P Positive Parenting Program for improving parent self-efficacy for managing their child's condition and condition-related behavioural problems, improving parent and family QoL, improving parenting style and reducing stress. There is also moderate evidence for the effectiveness of the Early Family Intervention Program for reducing perceived threat (threatened by parental situation), increasing confidence (confidence to receive help from others), increasing perceived spousal emotional support and reducing emotional distress, anxiety and depression. Finally, in terms of parent education programs, there is strong evidence of effectiveness in terms of improving parent anxiety in relation to caring for their child, as well as parental coping, and moderate evidence of effectiveness in terms of improving parent QoL.

Finally, the methodological quality of the included studies varied greatly. Of the 12 effective studies, two were judged to be of strong methodological quality, four moderate and six weak. Lack of blinding in particular was a key issue across all studies. Blinding (where the participants and/or outcome assessors are unaware of group allocation) aims to reduce detection and performance bias. Without blinding, participants and/or outcome assessors may influence the results of the study (consciously or not). This can result in an overestimation of effects and impact conclusions (Karanicolas, Farrokhyar, & Bhandari, 2010). However in the social sciences, it can often be difficult or nearly impossible to implement blinding due to logistic, methodological and/or ethical constraints (Renjith, 2017). Nevertheless, it is imperative that researchers in this field strive to conduct blind trials whenever possible. At the very minimum, researchers should be transparent in reporting clearly if and how blinding was employed. This is necessary in order to move the field towards more methodologically rigorous research that can be used to reliably inform evidence-based practice.

4.2 | Limitations of current review

This review has several limitations. First, only controlled studies were included, and those without a control/comparison group were excluded. This method was selected by authors because controlled studies can reduce the likelihood of bias (Kendall, 2003). However, the authors acknowledge that single-sample studies hold value and can offer useful insights – insights that this review may have missed. Second, although mixed-methods studies were included, the authors of this review did not analyse qualitative results. Again, the authors acknowledge that qualitative findings can be useful in providing rich insight into a given topic. This is particularly the case in relation to intervention acceptability; another element that was not commented on within this review. In addition, this review did not explore or comment on cost effectiveness of interventions. Within a context of limited resources for healthcare and even more so within the field of psychology, it is important to obtain a good understanding about 'value for money' in order to assist decision-makers in selecting the interventions, which maximise outcomes for the available resources (Hutubessy, Chisholm, Edejer, & WHO-CHOICE, 2003; Weatherly et al., 2009). Further, most studies in this review (12/15) reported some evidence of effectiveness. It is possible that a publication bias may have occurred, as studies with significant findings are more likely to be accepted for publication (Rosenthal, 1979). This is problematic as it can inflate the evidence of effectiveness. Although the authors of the current review took measures to reduce this risk, including conducting grey literature searches as well as contacting experts in the field, it is important to interpret the findings of this review with this limitation in mind. It is also important to consider who the findings of the current review can be generalised to. Although included studies were carried out in a range of countries, they were all high-income or upper-middle income countries. The authors chose to apply these criteria in order to ensure relevance to Western healthcare systems. However, as a result, findings may not be applicable to parent populations from lower-income countries. Similarly although most studies did not report parent demographic information, from those that did, it is clear that samples were mostly made up of White mothers (with the exception of Morawska et al. (2017b) who included only fathers in their sample). As such, it is not possible to determine whether these interventions would be effective among other parent samples, including parents from minority ethnic and cultural backgrounds and fathers. Indeed, these parent population groups are often missed from the research (Nelson et al. 2012; Stock & Rumsey, 2015). Finally, the current review opted for a broad study population (i.e., parents and/or guardians of CYP (<18 years) with congenital or acquired AAHCs). As such, the 15 included studies looked at a number of conditions, including skin and congenital conditions, as well as acquired scarring. It could be argued that this group is too broad and that there is potential for condition-specific insights to be overlooked. However, the literature shows that CYP with AAHCs and their families experience more common rather than specific issues, irrespective of diagnosis or condition severity. This suggests that the provision of support for parents and families does not necessarily have to be individualised according to individual diagnosis or severity, and can instead focus on more broad concerns (Morawska, Calam, & Fraser, 2014; Phillips et al., 2007).

4.3 | Future directions

The current review highlights gaps in the methodology of evaluation studies, and the authors encourage future research to adopt more rigorous methodology in order to obtain a more reliable understanding of the evidence-base. Further, the authors recommend that future researchers strive for more diverse samples, including fathers and parents from Black and other minority ethnic and cultural backgrounds, in order to determine how effective interventions are across a range of parent populations. Future work should also aim to evaluate cost-effectiveness in order to determine which interventions offer the most opportunity for better outcomes with less resource. Last, future intervention evaluation research and/or systematic reviews of this kind should consider a mixed-methods approach, as well as an exploration of intervention acceptability.

5 | CONCLUSION

The current review is the first to explore interventions to improve psychosocial outcomes specifically among parents of CYP with AAHCs. This review finds moderate to strong evidence for the effectiveness of the Triple P Positive Parenting Program, the Early Family Intervention Program and parent education interventions. These findings may have useful implications for the delivery of current and development of future parent/family interventions. Methodological quality of included studies varied considerably, and lack of blinding was a particularly salient issue. A number of recommendations for future research are made including the need for more rigorous methodology, more diverse samples that include fathers and parents from minority backgrounds, mixed-methods approaches that allow for a consideration of intervention acceptability and an evaluation of intervention cost-effectiveness.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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