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Psychoeducation for children with chronic conditions: a systematic review and meta-analysis

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Abstract

Objective

This systematic review and meta-analysis evaluated the effectiveness of psychoeducational interventions in improving Quality of Life for children with chronic conditions.

Methods

We identified 25 randomised controlled trials of psychoeducational interventions for children with chronic conditions that reported a Quality of Life outcome and were published 1980-2018. Due to small numbers of interventions in other chronic conditions, comparisons between chronic conditions were limited to 17 studies addressing interventions for asthma and diabetes.

Results

Psychoeducational interventions were associated with a small, statistically significant improvement in Quality of Life (Standardised Mean Difference= 0.14; 95% Confidence Interval: 0.06 to 0.23). The effect was significantly larger for asthma interventions compared to diabetes interventions, and in interventions delivered to younger (under 12 years) rather than older children (12 years and over).

Conclusions

These results suggest that currently evaluated psychoeducational interventions improve Quality of Life for children with asthma but not for children with diabetes. Children with diabetes may require tailored interventions with additional components alongside psychoeducation. Further intervention studies are needed to generalise to other conditions and to draw conclusions about which settings and modes of delivery are most effective in improving Quality of Life.

Psychoeducation for children with chronic conditions: a systematic review and meta-analysis

Millions of children worldwide have chronic health conditions such as asthma and diabetes. These conditions place financial and psychological burdens on individuals, families and health services and lead to hospitalisations, activity limitations, school absences and anxiety (Holt, 2017; Lozier, Zahran & Bailey, 2019). Chronic conditions during childhood require long-term management by health professionals, families and children. Sub-optimal management is common, especially in adolescence, and can lead to poor long-term health outcomes (Murphy, Rayman & Skinner, 2006).

To improve treatment adherence and self-management for chronic health conditions, the child and family must develop complex skills. Asthma management requires knowledge about symptoms, triggers, medication and correct inhaler use (Gardner et al., 2015). Diabetes management involves maintaining optimal blood sugar levels in a daily regimen of blood monitoring, insulin dose adjustment and food intake (Phelan et al., 2018). Effective symptom management is also important for children with other chronic conditions (e.g. cancer, cystic fibrosis and eczema). These examples demonstrate the need for educational input and support from health professionals, to effectively manage chronic illness.

Psychoeducation teaches the knowledge and skills required to understand and manage illness. This broad definition can include interventions which address illness-specific self-management education as well as interventions which focus on generic coping skills, such as cognitive behavioural therapy and motivational interviewing (Barlow & Ellard, 2004). Psychoeducational interventions are often multicomponent, addressing factors such as peer support, family communication, action planning and monitoring alongside education.

Systematic reviews of psychoeducational interventions for children with chronic conditions highlight improvements in disease-related outcomes such as symptoms, self-efficacy and self-management with small to medium effect sizes (Boyd et al., 2009; Murphy et al., 2006), according to Cohen's (1988) conventions. However, results are heterogeneous, possibly reflecting heterogeneity in the content of the interventions themselves. In order to reduce this heterogeneity, we focus on psychoeducational interventions that deliver comprehensive self-management education. We include multicomponent psychoeducational interventions that primarily deliver disease self-management skills and knowledge.

In order to assess whether psychoeducational interventions are effective, appropriate outcome measures must be identified. Quality of Life (QoL) offers an appropriate outcome measure with which to assess the efficacy of psychoeducation in reducing the psychological burden of chronic illnesses and in facilitating the child's adjustment to their illness (Varni, Limbers & Burwinkle, 2007). QoL is a multidimensional construct capturing the impact of chronic conditions on physical, psychological, social, and emotional functioning (Eiser & Morse, 2001). Measuring QoL also allows the burdens of illness to be compared across different chronic conditions. Other self-management and knowledge outcomes are likely to be specific to particular conditions (e.g. glycaemic control in diabetes or lung function in asthma). Cross-sectional studies have found (positive) associations between effective self-management and children's QoL (Lozier et al., 2019; Piercy, Davies, Orozco & Chubb, 2015). Psychoeducation might reduce the burden of the child's illness and improve QoL by improving self-management, communication and involvement with healthcare providers.

Until recently there has been limited evidence available to evaluate the effect of psychoeducation on QoL, as QoL has not often been measured in the evaluation of these interventions (Barlow & Ellard, 2004; Boyd et al., 2009). Psychoeducational interventions have been documented to improve QoL for children with asthma, with a small effect size

(Standardised Mean Difference (SMD) = 0.27; 95% Confidence Intervals (CI): 0.18-0.36) (Harris et al., 2018). However, reviews of psychoeducation for children with other chronic conditions have reported inconsistent results or a lack of effect on QoL (e.g. Charalampopoulos et al., 2017; Stinson, Wilson, Gill, Yamada & Holt, 2009). This might suggest that psychoeducation can have different effects on QoL across pediatric chronic conditions. Specifically, there may be more scope for improvement in QoL for children with asthma than other illnesses that have been studied to date.

Given the inconsistencies in the literature regarding the size of the effect of psychoeducational interventions on QoL, there may be a number of other moderators of effectiveness which have not been adequately explored. Inclusion of a parent or caregiver might improve the effect of psychoeducational interventions. Non-adherence and poor self-management have been associated with negative family functioning and family conflict (Lewin et al., 2006; Lohan, Morawska & Mitchell, 2015). Therefore, interventions which also target family functioning may further improve self-management. Reviews have reported improvements in illness management, knowledge and family function for family interventions (Feldman et al., 2018; Law, Fisher, Fales, Noel & Ecclestone, 2014; Lohan et al., 2015). Family interventions may be particularly important for children with chronic conditions as responsibility for management shifts from the parent to the child during adolescence (Feldman et al., 2018). This suggests that the age of the child might also be a potential moderator. Non-adherence to treatment, poor self-management, negative family functioning and impaired QoL are more problematic during adolescence (Feldman et al., 2018; Varni et al., 2007). Therefore, psychoeducational interventions might have more potential to improve outcomes for an adolescent age group.

Time input (dosage) and duration of intervention delivery might also moderate intervention effectiveness. As the information required for effective self-management is

likely to require considerable input, it is possible that more intensive interventions may be more effective. However, reviews have been unable to identify optimal time inputs (Hood, Rohan, Peterson & Drotar, 2010). Other aspects of interventions which might moderate their effect include the setting (e.g. clinic, school, home) and whether it is presented in an individual or group context. Previous reviews of psychoeducational interventions have not been able to reach conclusions about the most effective modes of delivery (Murphy et al., 2006; Barlow and Ellard, 2004). Therefore, setting and grouping are explored in this review without directional hypotheses.

Reviews have often been limited by shortcomings in the existing literature which includes many uncontrolled and underpowered studies, poorly described interventions and inadequate reporting of results (Barlow & Ellard, 2004; Murphy et al., 2006). The use of a wide range of intervention targets and outcome measures has also hampered attempts to summarize the literature (Hilliard, Powell, Anderson & Kazak, 2016). We addressed these issues by reviewing interventions evaluated using a Randomised Controlled Trial (RCT) design and using QoL as an outcome measure, facilitating comparisons across studies.

This review aimed to quantify the effect of psychoeducation on the QoL of children with chronic conditions. We hypothesised that QoL would improve as a result of psychoeducation and that the effect would be largest for interventions delivered to children with asthma, as an effect in this group has been established. We also hypothesised that psychoeducational interventions would be more effective when delivered to older children (adolescents), when they were also delivered to a parent/caregiver and when interventions included more extensive time input, in terms of session frequency and duration.

Methods

Literature Search Strategy

Web of Science, PsycInfo, Medline (via Pubmed) and Cumulative Index of Nursing and Allied Health Literature (CINAHL) databases were searched for interventions published from 1st January 1980 to 12th August 2018. The first QoL scale developed to measure outcomes for children with chronic conditions was used in 1985 (Eiser and Morse, 2001), so our start date ensured all relevant studies would be included. Our search strategy used a PICO (Population, Intervention, Comparison group, Outcome) framework for searching the literature with search terms for Population (children with chronic illnesses), Intervention (psychoeducation), Comparison group (RCT with non-treatment control group) and Outcome (QoL). An example search strategy is provided in Supplementary materials.

Inclusion/exclusion criteria

Our goal was to identify RCTs which evaluated psychoeducational interventions delivered to children with chronic health conditions, which reported QoL as an outcome, using a validated measure. We first eliminated studies that did not target children (up to age 18) with chronic physical health conditions. Next, we eliminated studies that were not RCTs comparing a psychoeducational intervention to a non-education control group. Studies comparing other treatments (e.g., motivational interviewing) to psychoeducational interventions were excluded as other interventions may also improve QoL, thus underestimating the effect of psychoeducation on QoL. We then eliminated studies which did not use a validated QoL outcome measure (published details were required regarding reliability, applicability and validity of the measure). Measures could be generic or illness-specific and self or parent-reported (self-reported and illness-specific measures were given preference in studies using multiple approaches).

Data extraction and management

Titles and abstracts were screened by MD (initials indicate the reviewer responsible for each aspect of data management). Full text articles were screened for inclusion (MD) and a random 10% sample screened by a second reviewer (LCE) with an initial 87% agreement rate. All disagreements were resolved through discussion. Data extraction was carried out using a piloted form (MD) with a 20% sample audited by another reviewer (PP) giving an initial 92% agreement rate. Means and standard deviations for the total QoL scale or data from which these could be calculated were extracted for meta-analysis. Authors were contacted if data was omitted. Supplementary Table 1 summarises and references the QoL scales used by the studies in this review. The data for meta-analysis were independently extracted by two reviewers (MD, LCE) with an initial agreement of 80%. The remaining 20% was re-extracted to give a final dataset with full agreement.

Risk of bias assessment

Risk of bias was assessed, (MD) using the Cochrane systematic reviews tool (Higgins et al., 2011), as high, low or unclear for selection bias (random sequence generation, group allocation concealment), performance and detection bias (blinding of participants and researchers to group allocation), attrition bias (loss of participants during the study), reporting bias (full reporting of outcomes) and cluster design bias (cluster randomisation, cluster baseline imbalance, cluster attrition). A random sample of 25% was assessed by a second reviewer (LCE) with an initial agreement of 80.4%. A funnel plot (plotting effect size against standard error) was used to check for publication bias (Sterne et al., 2011).

Data synthesis

Data was analysed using Revman 5.3 (The Cochrane Collaboration, 2014). Effect sizes were calculated as the Standardized Mean Difference (SMD) between intervention and

control groups post-intervention (Cohen's d) (Cohen, 1988). The meta-analysis used a random effects model (Borenstein, Hedges, Higgins & Rothstein, 2010). To avoid over-weighting cluster RCTs, a design effect was calculated: $1+(M-1)ICC$ (M = average cluster size, ICC = intraclass correlation). The sample size was divided by this design effect to give an effective sample size (McKenzie, Ryan & Di, 2016). A pooled effect size (SMD) and measure of heterogeneity (I^2) were calculated for all analyses. Moderators were tested in subgroup analyses for chronic condition (asthma, diabetes), intervention setting (clinic, school, home), grouping (individual, group), inclusion of a caregiver (included, not included).

The subgroup analysis for age compared pre-adolescent children (younger than 12 years) with children aged 12 years and over. Twelve years was used to differentiate between childhood and adolescence. Adolescence has been identified as a period of difficulty in managing chronic illnesses (Lewin et al., 2006; Lohan et al., 2015). The cut-off of 12 years reflected the groupings of the included studies and was partly pragmatic. There were insufficient studies to form a separate middle childhood (e.g. 10-12 years) subgroup. Age range and mean age were used to allocate studies which had a mixed age range.

As there is little evidence for optimal doses of psychoeducational interventions, the subgroups used to distinguish between time inputs were defined pragmatically: 7 studies were up to 3 hours and 7 were over 4 hours. National Institute for Health and Care Excellence guidelines (NICE, 2013) for length of behaviour change interventions were used to distinguish duration subgroups (short: <3 months, medium: 3 months-1 year). Subgroup analyses evaluated biases due to study design (RCT, cluster RCT), type of control group (usual care, wait list, attention) and study quality (high risk of bias, no high risk of bias).

Some QoL measures have conventions for calculating a Minimal Clinically Important Difference (MCID) that patients perceive to be beneficial and which would mandate a change

in the patient's management (Jaeschke, Singer & Guyatt, 1989). Where possible, pre and post-intervention scores were used to calculate whether an MCID had been achieved.

Results

Characteristics of included studies

Database searches and contact with authors identified 19,660 studies as shown in Figure 1; PRISMA flow diagram (Moher et al., 2009). Full texts were read for 198 papers, 173 of which were excluded, leaving 25 in the review. Reasons for exclusion were; non-RCTs (49 studies), no child QoL outcome (45), delivered to adults (21), duplicate studies (11), inadequate data to calculate an effect size (20), not psychoeducation (25), unable to source full text of paper (2). Attempts to contact authors were made before excluding on the basis of inadequate data or unavailability. The 25 included studies were delivered to children with 7 chronic conditions: asthma (10 studies), diabetes (7), juvenile arthritis (2), eczema (3), cystic fibrosis (1), epilepsy (1) and cancer (1). Supplementary Table 2 provides detailed data extracted from the full text papers of these 25 studies. Apart from asthma and diabetes it was not possible to form subgroups containing the other chronic conditions and the subgroup analyses were calculated using only the asthma and diabetes studies. Table 1 summarises the characteristics of the 17 asthma and diabetes studies.

Risk of bias

Six studies were judged at high risk for attrition bias (Almomani et al., 2017; Boogerd, Noordam, Kremer, Prins & Verhaak, 2014; Butz et al., 2005; Henry, Gibson, Vimpani, Francis & Hazell, 2004; Murphy, Wadham, Hassler-Hurst, Rayman & Skinner, 2012; Price et al., 2016). These studies only analysed children who completed the intervention, had high attrition, were unbalanced between groups or reported attrition that could be related to outcomes (e.g. worse QoL at baseline). Eleven of the studies had no

identified source of high bias. A funnel plot (available on request) showed the larger more precise studies were close to the pooled effect size, there was little asymmetry and the small imprecise studies were not over-estimating the effect size. Therefore, there was no evidence of systematic biasing of the estimated effect due to studies being missing from the available literature (Sterne et al., 2011).

Analysis of pooled effect sizes

Across the 25 eligible studies there were 2536 participants in an intervention condition and 2372 in a control condition. The pooled effect size (*SMD*) was 0.14 (95% *CI*: 0.07 to 0.20). The overall effect was significant ($Z=3.91$, $p= 0.0001$), indicating that psychoeducational interventions significantly improved QoL, with a small effect size (Cohen, 1988). After removing the 8 studies which could not be subgrouped into chronic condition, the pooled effect size (*SMD*) for the asthma and diabetes studies (intervention $n=2143$, control $n=1996$) was 0.14 (95% *CI*: 0.06 to 0.23). The forest plot for these studies is shown in Figure 2. Effect sizes ranged from -0.19 to 0.54. The overall effect was small but significant ($Z=3.39$, $p=0.0007$) (Cohen, 1988). Heterogeneity was non-significant ($\chi^2= 24.06$, $df=16$, $p=0.09$, $I^2=33\%$). However, non-significant heterogeneity does not necessarily indicate an absence of clinical heterogeneity (Groenwold, Rovers, Lubsen & Heijden, 2010) and the subgroup analyses were carried out as planned.

Moderator effects of chronic condition and age

There was a significant subgroup difference between chronic conditions ($\chi^2= 6.25$, $df=16$, $p=0.01$, $I^2= 84\%$). Interventions for asthma were more effective (10 studies, $n= 3201$; *SMD*= 0.21, 95% *CI*: 0.11 to 0.30) than diabetes interventions (7 studies, $n= 938$; *SMD*= 0.00, 95% *CI*: -0.12 to 0.13). All the asthma studies used the PAQLQ (Pediatric Asthma Quality of Life Questionnaire). Compared to baseline scores, 6 out of 7 asthma studies had

achieved an MCID in the intervention group (see Supplementary Table 3 for MCID calculations). MCIDs could not be calculated for 3 asthma studies which did not report baseline data or did not use standard scoring. Two studies reported an MCID in the control group. There was a significant subgroup difference for child age ($\chi^2= 4.70$, $df=16$, $p=0.03$, $I^2= 78.7\%$) with a larger effect in the younger children (<12 years) (8 studies, $n=2451$: $SMD=0.23$, 95% CI : 0.11 to 0.35) compared to the older children (12+ years) (9 studies, $n=1688$; $SMD= 0.06$, 95% CI : -0.03 to 0.16).

Moderator effects of setting, dosage/duration and group context of intervention

Effect sizes did not differ on the basis of setting (school vs clinic; 2 home-based interventions did not fit into either sub-group) ($n=4043$, $\chi^2= 3.17$, $df=14$, $p=0.07$, $I^2= 68.5\%$), delivery to individual or group ($n=3707$, $\chi^2= 0.30$, $df=14$, $p=0.59$, $I^2= 0\%$) or whether a parent/caregiver participated in the intervention ($n=4139$, $\chi^2= 0.33$, $df=16$, $p=0.57$, $I^2= 0\%$). There were no subgroup differences for intervention dose (shorter: up to 3 hours vs. longer: 4 hours and over; 3 studies did not define a time input) ($n=3582$, $\chi^2= 0.03$, $df=13$, $p= 0.85$, $I^2= 0\%$) or intervention duration (over 3 months vs. under 3 months) ($n=3520$, $\chi^2= 3.35$, $df=14$, $p=0.07$, $I^2= 70.1\%$). There was a significant effect of intervention dose in the asthma interventions ($n=3201$, $\chi^2= 8.47$, $df=9$, $p= 0.004$, $I^2= 88.2\%$). Longer interventions (4 hours and over) had a larger effect (5 studies, $n=1800$, $SMD=0.31$, 95% CI : 0.22 to 0.41) than shorter interventions (up to 3 hours) (5 studies, $n=1401$, $SMD=0.10$, 95% CI : 0.00-0.21). There were insufficient studies to subgroup longer and shorter interventions within the diabetes interventions.

Moderator effects of study design

Effect sizes did not differ between the 9 RCTs and 8 cluster RCTs ($n=4139$; $\chi^2= 1.17$, $df=16$, $p=0.28$, $I^2=14.9\%$) or the type of control group used; usual care (9 studies) compared

to wait-list control (5 studies) ($n= 3856$; $\chi^2= 1.34$, $df=13$, $p=0.25$, $I^2=25.2\%$) (2 studies using attention control groups could not be subgrouped). Effect sizes did not differ between studies with high risk of attrition bias (6 studies) and those with low or unclear risk (11 studies) ($n=4139$; $\chi^2=0.85$, $df=16$, $p=0.36$, $I^2= 0\%$).

Discussion

Our meta-analysis indicated that there was a significant effect of psychoeducational interventions on QoL for children with chronic physical conditions across the 25 included RCTs. However, the effect size was small and subgroup analyses indicated that this effect held for children with asthma but not for children with diabetes. Unfortunately, there were insufficient RCTs with QoL outcomes to analyse whether psychoeducation was effective in improving QoL for children with other chronic conditions.

It is necessary to interpret effect sizes in terms of clinical significance and relevance to children and families. The *SMD* of 0.21 reported for the asthma interventions is comparable to the effect size reported by Harris et al. (2018) for school-based asthma interventions (*SMD*= 0.27). Cohen's (1988) guidelines would classify these *SMDs* as small effects. However, Cohen's levels are arbitrary and do not necessarily translate into clinical significance. Small to medium effects have been reported to be beneficial in chronic illness interventions (Hilliard et al., 2016). In the current review, clinically meaningful improvements were achieved in 6 out of 7 asthma studies, which suggests that psychoeducation is an effective method of improving QoL for children with asthma.

The lack of effect of psychoeducation in the diabetes interventions may reflect differences in the burden of treatment and in the information needed for effective self-management of this condition relative to asthma. As shown in Table 1, the information in the asthma interventions covered the pathophysiology of asthma, trigger identification and

avoidance, proper use of medications and inhalers, managing an asthma exacerbation, lifestyle, exercise and asthma action planning. It may be that this information is adequate to improve adherence and enable effective management. Children with asthma who are using the correct preventative medication and understand how to avoid triggers may have few daily symptoms and experience better QoL. A possible effect of time input was detected for the asthma interventions, favouring longer interventions (4 hours and over). This may indicate the most effective time input and content for psychoeducational interventions, which could be explored in future research.

The information in the diabetes interventions included carbohydrate counting, blood glucose monitoring, insulin adjustment and lifestyle factors. This information is necessary for effective diabetes self-management but may not be sufficient. Treatment for diabetes involves frequent daily monitoring and complex calculations to deliver the correct dose of insulin in relation to carbohydrate intake and activity levels. It might be that the information required for effective diabetes management is too complex for children to assimilate in these formats.

It is also possible that the diabetes interventions were too general to meet individual needs. It has been argued that diabetes psychoeducation needs to be tailored to individual families and targeted to at-risk groups (Feldman et al, 2018). As the diabetes interventions were structured educational programs this may not have allowed information to be tailored to individuals. The results of targeting to particular groups was inconsistent in this review. Price et al. (2016) reported better outcomes for a subgroup with poorer glycaemic control at baseline. However, Christie et al.'s (2014) intervention was targeted to children with poor control but did not improve QoL or glycaemic control. The results were also mixed for the asthma studies with some targeted interventions producing larger effect sizes (Bowen, 2013; Butz et al.,2005). Unfortunately, there were insufficient studies to examine the effect of

targeting in subgroup analyses, particularly as some were targeted according to disease severity and others to vulnerable socioeconomic groups.

Diabetes interventions may require a greater focus on approaches which provide the coping skills and motivation necessary to apply diabetes knowledge. For example, approaches such as motivational interviewing, coping skills training and cognitive behavioural techniques, which provide counselling, cognitive reframing and coping strategies, may improve the impact of psychoeducation on health behaviours. Reviews have reported improved outcomes for children with chronic conditions from interventions which target these psychological processes alongside self-management skills (Barlow & Ellard, 2004; Charalampopoulos et al., 2017; Hilliard et al., 2016). Motivational interviewing has been recommended to support treatment adherence and improving glycaemic control in recent diabetes management guidelines (Delamater et al., 2018). The need for multicomponent interventions which include psychological input is reflected in consensus guidelines for diabetes education in children and adolescents, which recommend the inclusion of coping skills, communication skills and problem-solving skills training alongside self-management education. Family-based behavioural interventions to promote appropriate family involvement and support, which utilise goal setting and negotiation of realistic management goals may also be necessary (Delamater et al., 2018; Phelan et al., 2018). These guidelines suggest that education and additional support should be integrated into clinical care and be provided as an on-going process.

It is also possible that variation in intervention content may have contributed to the non-significant effect for the diabetes interventions. For example, some included family teamwork while others did not. Further research to evaluate different components within psychoeducational interventions (e.g. dismantling/constructive studies) may be necessary to identify necessary and sufficient components of interventions for children with diabetes.

We hypothesised that older children would benefit more from psychoeducation. However, it was the interventions delivered to the younger group which were more effective. Age may be conflated with condition as the asthma interventions were predominantly delivered to the younger children. However, it could also reflect a real age difference. QoL is often more impaired in adolescents than younger children, in a range of chronic conditions (Moreira et al., 2013; Varni et al., 2007). We hypothesized that this greater psychological burden might lead to larger improvements in QoL after psychoeducational interventions. However, it may be that QoL is more resistant to change in adolescence. Physiological changes, peer issues, family conflict, academic pressures and increased risk-taking behaviours during adolescence may independently affect the child's QoL, impair their illness self-management and make it more difficult to intervene effectively. Future intervention studies could explore whether psychoeducation targeted to younger children with diabetes might have a larger effect on QoL. The younger children with diabetes in this review (under 12 years) were included in interventions with adolescents. This might also have affected the age-appropriateness of the intervention for both the younger and older children.

We hypothesized that we would find a larger effect of psychoeducation with the inclusion of a parent/caregiver. However, no effect was observed. Various reviews have reported the effectiveness of family interventions in improving outcomes for children (Feldman et al., 2018; Lohan et al., 2015). However, Feldman et al. (2018) also suggested that the pathways for effectiveness in family interventions have not been identified. It is likely that family involvement is effective in some types of interventions, but it was not sufficient to improve outcomes for the interventions in this review.

Another explanation for the larger effect of the asthma interventions on QoL might be the outcome measure used. The PAQLQ was used in all the asthma studies and it may be more sensitive to treatment effects than the diabetes measures. A range of measures were

used in the diabetes studies (see Supplementary Table 1). Two studies used only a generic scale which could make illness-specific changes harder to detect. We also examined whether study methodology and quality influenced effect size. The results from the funnel plot, risk of bias and methodological subgroup analyses suggest that our evidence is generally good, particularly in comparison to previous reviews (Barlow & Ellard, 2004; Murphy et al., 2006). The importance of the RCT design was demonstrated by the improvements in control groups observed in this review which show that improvements in outcomes might not be intervention-related.

The studies had no source of high bias other than attrition (6 studies), and the subgroup analysis for this was not significant. However, attrition is problematic. In combination with low sample size, it means that studies are often underpowered. Effect sizes in psychoeducational interventions tend to be small, which means that larger samples are required. However, many of the studies in this review had very small sample sizes. While synthesizing studies using meta-analysis helps to reduce the problem of small sample sizes, it does not remove attrition bias. Attrition is often higher in groups with more severe disease, lower initial QoL, lower socioeconomic status and ethnic minority groups (Charalampopoulos et al., 2017; McGhan et al., 2010). This may mean that those with the greatest potential for improvement are lost, leading to an under-estimation of the potential effect of interventions and reducing the generalisability of findings. Intervention delivery may need to be modified to engage these children and families, using culturally tailored and/or flexible education methods and methods of recruitment.

Limitations

Asthma and diabetes are the most common chronic childhood conditions, so it is appropriate that they represent the majority of targets for intervention. However, as only a

small number of chronic conditions were addressed, generalisation to less common chronic conditions is limited. Psychoeducational interventions have been trialled in a wide range of other chronic conditions (e.g. lupus, sickle cell anaemia, multiple sclerosis) which could not be included in this review due to a lack of RCTs. Our sole inclusion of RCTs, while a strength of the review, may mean that novel or promising interventions which have not yet been rigorously evaluated were excluded.

The review was also limited by the number of diabetes and asthma studies. Many subgroups contained a small number of studies, meaning that moderator analyses may have been underpowered to detect differences. Subgroup analyses may have been conflated with chronic condition and we were unable to explore whether modes of delivery had differential effects within conditions. With a larger number of intervention studies, future reviews might be able to examine additional potential moderators such as illness severity, time elapsed since diagnosis, targeting to at-risk groups, additional age groups and length of follow-up.

An inevitable limitation of all reviews is that they can only include work published up to a specified date. Our review includes papers published up to August 2018. We re-ran our searches on the original databases at the final manuscript revision stage (January 2020) and found 4 additional studies that met inclusion criteria (diabetes: 1 study, asthma: 2, juvenile arthritis: 1). In line with our conclusions, the diabetes intervention did not improve QoL (ES: -0.11, Brorsson, Leksell, Andersson & Lindholm, 2019) while the asthma interventions reported significant improvements in QoL (ES: not calculable on published data, Montalbano et al., 2019; ES: 0.16, Mosenzadeh, Ahmadipou, Mardani, Ebrahimzadeh & Shahkarami, 2019). Therefore, the most recently published studies are consistent with the results of our meta-analysis. An intervention for children with arthritis (Pilevar, Ramezani, Malek & Vashani, 2019) reported a substantial positive effect for psychoeducation (ES:1.75) which highlights the importance of evaluating interventions in a broader range of conditions.

Implications for practise

Psychoeducation is associated with an improvement in QoL for children with asthma. In most studies this was enough to achieve an MCID which suggests that this should be incorporated into routine care. A number of psychoeducational programs are available (e.g. ‘Roaring Adventures of Puff’; McGhan et al., 2010) While the effect size (*SMD*) of 0.21 is likely to be beneficial, it may be possible to improve this further by incorporating additional components and exploring optimal time inputs.

The effectiveness of psychoeducation on QoL outcomes in diabetes interventions has not been demonstrated in this review. Psychoeducation is vital for diabetes self-management. However, interventions may be more effective when they are tailored to individual needs and incorporate psychological components. Multicomponent interventions should be evaluated to assess which combinations are effective for children with diabetes. Future reviews could explore whether subgroup differences between chronic conditions are also evident in multicomponent interventions which include psychological components.

It is important that interventions are able to engage young people, to improve the recruitment of harder to reach children, particularly those with poor management, low QoL, and those from lower socioeconomic or ethnic minority backgrounds. Not including these children is likely to underestimate the potential of interventions and reduce the generalisability of research. It also indicates potential challenges in translating intervention research into clinical practise.

References

References marked with an asterix indicate studies included in the meta-analysis.

* Almomani, B., Mayyas, R., Ekteish, F., Ayoub, A., Ababneh, M., & Alzoubi, S., (2017).

The effectiveness of clinical pharmacist's intervention in improving asthma care in children and adolescents: Randomized controlled study in Jordan. *Patient Education and Counseling*, 100(4), 728-735.

Barlow, J., & Ellard, D. (2004). Psycho-educational interventions for children with chronic disease, parents and siblings: An overview of the research evidence base. *Child: Care, Health and Development*, 30(6), 637-645.

*Boogerd, E., Noordam, C., Kremer, J., Prins, J., & Verhaak, C. (2014). Teaming up:

Feasibility of an online treatment environment for adolescents with type 1 diabetes. *Pediatric Diabetes*, 15(5), 394-402.

Borenstein, M., Hedges, L., Higgins, J., Rothstein, H. (2010). Introduction to fixed-effect and random-effects models meta-analysis. *Research Synthesis Methods*, 1(2), 97-111.

*Bowen, F. (2013). Asthma Education and Health Outcomes of Children Aged 8 to 12 Years. *Clinical Nursing Research*, 22(2), 172-185.

Boyd M., Lasserson T., McKean M., Gibson P., Ducharme F., & Haby M. (2009).

Interventions for educating children who are at risk of asthma-related emergency department attendance, *Cochrane Database*, 15;(2).

Brorsson, A., Leksell, J., Andersson, M., & Lindholm, A. (2019). A person-centered education for adolescents with type 1 diabetes—A randomized controlled trial. *Pediatric Diabetes*, 20(7), 986-996.

- *Bruzzeese, J., Sheares, B., Vincent, E., Du, Y., Sadeghi, H., Levison, M., Evans, D. (2011). Effects of a school-based intervention for urban adolescents with asthma. A controlled trial. *American Journal of Respiratory and Critical Care Medicine*, 183(8), 998-1006.
- *Butz, A., Pham, L., Lewis, L., Lewis, C., Hill, K., Walker, J., & Winkelstein, M. (2005). Rural Children with Asthma: Impact of a Parent and Child Asthma Education Program. *Journal of Asthma*, 42(10), 813-821.
- *Cano-Garcinuño, A., Díaz-Vázquez, C., Carvajal-Urueña, I., Praena-Crespo, M., Gatti-Viñoly, A., García-Guerra, I., (2007). Group education on asthma for children and caregivers: a randomized, controlled trial addressing effects on morbidity and quality of life. *Journal of Investigational Allergology & Clinical Immunology*.17(4), 216-26.
- Charalampopoulos, D., Hesketh, K., Amin, R., Paes, V., Viner, R., & Stephenson, T. (2017). Psycho-educational interventions for children and young people with Type 1 Diabetes in the UK: How effective are they? A systematic review and meta-analysis. *PloS One*, 12(6).
- *Christie, D., Thompson, R., Sawtell, M., Allen, E., Cairns, J., Smith, F., Viner, R. (2014). Structured, intensive education maximising engagement, motivation and long-term change for children and young people with diabetes, *Health Technology Assessment*,18(20).
- *Cicutto, L., Murphy, S., Coutts, D., O'Rourke, J., Lang, G., Chapman, C., & Coates, P. (2005). Breaking the access barrier: Evaluating an asthma center's efforts to provide education to children with asthma in schools. *Chest*, 128(4), 1928-1935.

- *Cicutto, L., To, T., & Murphy, S. (2013). A Randomized Controlled Trial of a Public Health Nurse-Delivered Asthma Program to Elementary Schools. *Journal of School Health, 83*(12), 876-884.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Delamater, A., De Wit, M., McDarby, V., Malik, J., Hilliard, M., Northam, E., & Acerini, C. (2018) ISPAD Clinical Practice Consensus Guidelines: Psychological Care of Children and Adolescents with T1 Diabetes. *Pediatric Diabetes 19* (S27), 237-49.
- Eiser, C., & Morse, R. (2001). A review of measures of quality of life for children with chronic illness. *Archives of Disease in Childhood, 84*(3), 205-20511.
- Feldman, M., Anderson, A., Shapiro, L., Jedraszko, M., Evans, J., Weil, B., Weissberg-Benchell, M. (2018). Family-Based Interventions Targeting Improvements in Health and Family Outcomes of Children and Adolescents with Type 1 Diabetes: A Systematic Review. *Current Diabetes Reports, 18*(3), 1-12.
- Gardner, A., Kaplan, B., Brown, W., Krier-Morrow, D., Rappaport S., Marcus, L.,...Aaronson, D., (2015) National standards for asthma self-management education. *Annals of Allergy Asthma & Immunology, 114*(3):178-186.
- Groenwold, R., Rovers, M., Lubsen, J., & Heijden, G. (2010). Subgroup effects despite homogeneous heterogeneity test results. *Medical Research Methodology, 10*(1), 43.
- Harris, K., Kneale, D., Lasserson, T., McDonald, V., Thomas, J., & Grigg, J. (2018). School-based self-management educational interventions for asthma in children and adolescents: A systematic review. *Journal Of Allergy And Clinical Immunology, 141*(2), AB207.

- *Henry, R., Gibson, P., Vimpani, G., Francis, J., & Hazell, J. (2004). Randomized controlled trial of a teacher-led asthma education program. *Pediatric Pulmonology*, 38(6), 434-442.
- Higgins, J., Altman, D., Gøtzsche, P., Jüni, P., Moher, D., Oxman, A., Sterne, J. (2011). The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *British Medical Journal*, 343(7829), 889-893.
- Hilliard, M., Powell, P., Anderson, B., & Kazak, A. (2016). Evidence-Based Behavioral Interventions to Promote Diabetes Management in Children, Adolescents, and Families. *American Psychologist*, 71(7), 590-601.
- Hood, K., Rohan, J., Peterson, C., & Drotar, D. (2010). Interventions with adherence-promoting components in pediatric type 1 diabetes: Meta-analysis of their impact on glycemic control. *Diabetes Care*, 33(7), 1658-1664.
- Holt, R. (2017). The burden of diabetes self-management in children and young adults. *Diabetic Medicine*, 34(6), 747.
- *Horner, S., & Brown, A. (2014). Evaluating the effect of an asthma self-management intervention for rural families. *Journal of Asthma*, 51(2), 168-177.
- Jaeschke, R., Singer, J., & Guyatt, G., (1989). Measurement of health status: Ascertaining the minimal clinically important difference. *Controlled Clinical Trials*, 10(4), 407-415.
- *Katz, M., Volkening, L., Butler, D., Anderson, B., & Laffel, L. (2014). Family-based psychoeducation and care ambassador intervention to improve glycemic control in youth with type 1 diabetes: A randomized trial. *Pediatric Diabetes*, 15(2), 142-150.

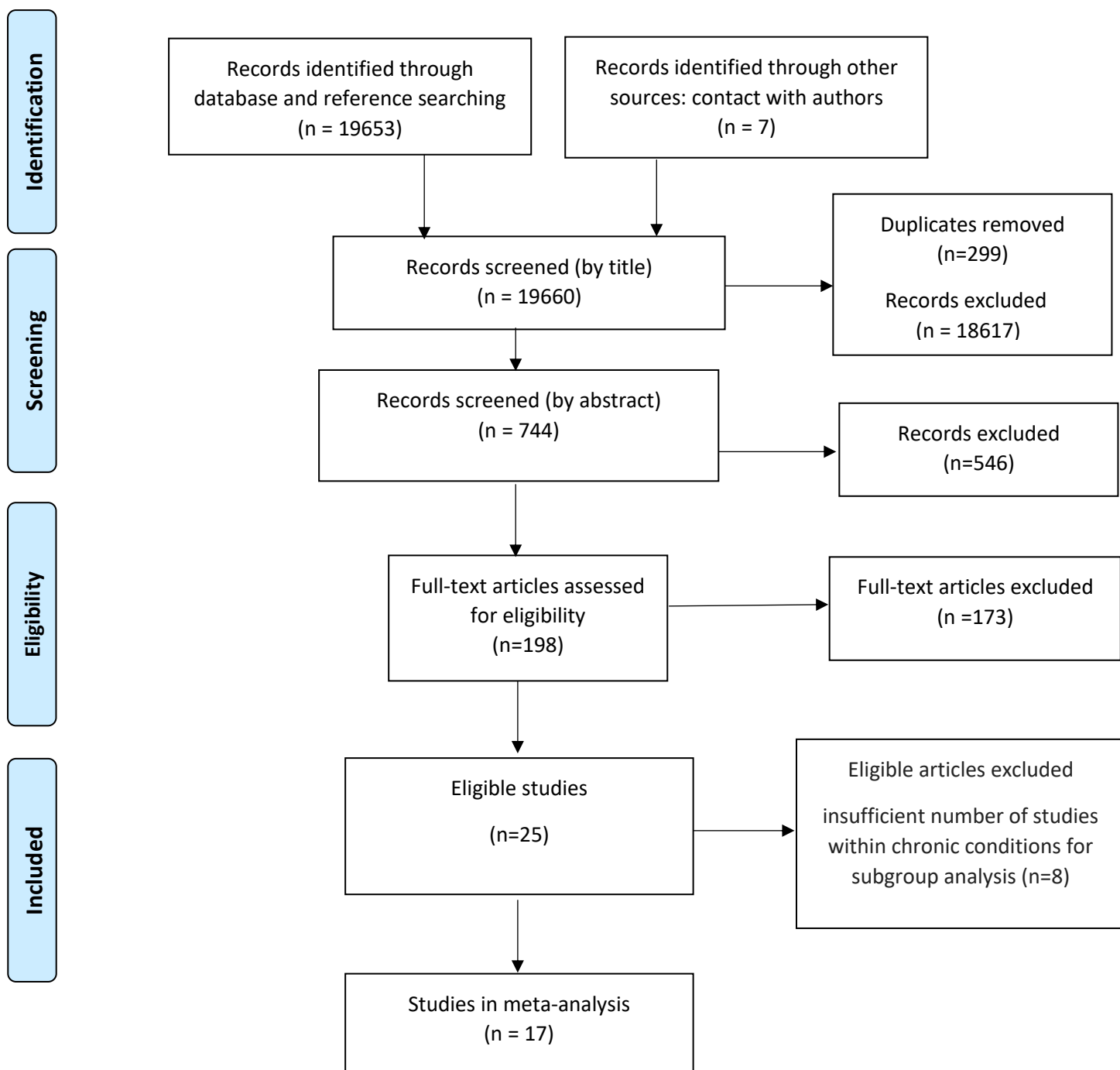
- *Laffel, L., Vangsness, L., Connell, A., Goebel-Fabbri, A., Butler, D. & Anderson, B., (2003). Impact of ambulatory, family-focused teamwork intervention on glycemic control in youth with type 1 diabetes. *Journal of Pediatrics*, 142(4), 409-416.
- Law, E., Fisher, E., Fales, J., Noel, M., & Eccleston, C. (2014). Systematic Review and Meta-Analysis of Parent and Family-Based Interventions for Children and Adolescents With Chronic Medical Conditions. *Journal of Pediatric Psychology*, 39(8), 866-886.
- *Lawson, M., Cohen, N., Richardson, C., Orrbine, E., & Pham, B. (2005). A randomized trial of regular standardized telephone contact by a diabetes nurse educator in adolescents with poor diabetes control. *Pediatric Diabetes*, 6(1), 32-40.
- Lewin, A., Heidgerken, A., Geffken, G., Williams, L., Storch, E., Gelfand, K., & Silverstein, J. (2006). The Relation Between Family Factors and Metabolic Control: The Role of Diabetes Adherence. *Journal of Pediatric Psychology*, 31(2), 174-183.
- Lohan, M., Morawska, A. & Mitchell, A., (2015). A systematic review of parenting interventions for parents of children with type 1 diabetes. *Child: Care, Health and Development*, 41(6), 803-817.
- Lozier, M., Zahran, H., Bailey, C. (2019). Assessing health outcomes, qol and healthcare use among school-age children with asthma. *Journal of Asthma*, 56(1), 42-49.
- McGhan, S., Wong, E., Sharpe, H., Hessel, P., Mandhane, P., Boechler, V., Befus, A. (2010). A children's asthma education program: Roaring Adventures of Puff (RAP), improves quality of life. *Canadian Respiratory Journal*, 17(2), 67-73.
- McKenzie J, Ryan R, Di T., (2016) Cochrane Consumers and Communication Review Group. 'CCCRG: cluster randomised controlled trials' <http://cccr.org.cochrane.org>.

- Moher, D., Liberati, A., Tetzlaff, J., Altman, D., Antes, G., Atkins, D., Tugwell, P. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Annals of Internal Medicine*, 151(4), 264-269.
- Montalbano, L., Ferrante, G., Cilluffo, G., Gentile, M., Arrigo, M., La Guardia, D., . . . La Grutta, S. (2019). Targeting quality of life in asthmatic children: The MyTEP pilot randomized trial. *Respiratory Medicine*, 153, 14-19.
- Moreira, H., Carona, C., Silva, N., Frontini, R., Bullinger, M., & Canavarro, M., (2013). Psychological and Quality of Life Outcomes in Pediatric Populations: A Parent-Child Perspective. *The Journal of Pediatrics*, 163(5), 1471-1478.
- Mosenzadeh, A., Ahmadipour, S., Mardani, M., Ebrahimzadeh, F., & Shahkarami, K. (2019). The Effect of Self-Care Education on the Quality of Life in Children with Allergic Asthma. *Comprehensive Child and Adolescent Nursing*, 42(4), 304-312.
- Murphy, H., Rayman, G., & Skinner, T. (2006). Psycho-educational interventions for children and young people with Type 1 diabetes. *Diabetic Medicine*, 23(9), 935-943.
- *Murphy, H., Wadham, C., Hassler-Hurst, J., Rayman, G., & Skinner, T. (2012). Randomized trial of a diabetes self-management education and family teamwork intervention in adolescents with Type1 diabetes. *Diabetic Medicine*, 29(8), 249-254.
- NICE Guidance (2013), Behaviour Change Draft Guidance. PH49. London: National Institute for Health and Care Excellence (UK).
- Phelan, H., Lange, K., Cengiz, E., Gallego, P., Majaliwa, E., Pelicand, J., ... & Hofer, S. E. (2018). ISPAD Clinical Practice Consensus Guidelines 2018: Diabetes education in children and adolescents. *Pediatric Diabetes*, 19 (S27), 75-83.

- Piercy, M., Davies, D., Orozco, B., Chubb, J. (2015). The Relationship Between Glucose-Lowering Medications, Adherence, and Outcomes in Patients with Type 2 Diabetes. *Value in Health, 18*(7), 343.
- Pilevar, N., Ramezani, M., Malek, A., & Vashani, H. (2019). Effect of Implementing Family-centered Empowerment Model on the Quality of Life in School-age Children Diagnosed with Rheumatoid Arthritis. *Journal of Evidence-Based Care, 9*(2), 64–73.
- *Praena-Crespo, M., Aquino-Llinares, N., Fernandez-Truan, J.C., Castro-Gomez, L., Segovia-Ferrera, C. (2017). Asthma education taught by physical education teachers at grade schools. *Allergologia & Immunopathologia. 45* (4): 375-386.
- *Price, K., Knowles, J., Fox, M., Wales, J., Heller, S., Eiser, C., & Freeman, J. (2016). Effectiveness of the Kids in Control of Food (KICK-OFF) structured education course for 11–16 year olds with Type 1 diabetes. *Diabetic Medicine, 33*(2), 192-203.
- Sterne, J., Sutton, A., Ioannidis, J., Terrin, N., Jones, D., Lau, J., Higgins, J. (2011). Recommendations for examining and interpreting funnel plot asymmetry in meta-analyses of randomised controlled trials. *British Medical Journal, 343*(7818), 302-7.
- Stinson, J., Wilson, R., Gill, N., Yamada, J., Holt, J., (2009) A Systematic Review of Internet-based Self-Management Interventions for Youth with Health Conditions, *Journal of Pediatric Psychology, 34* (5), 495–510.
- The Cochrane Collaboration (2014). Review Manager (RevMan) Version 5.3. Copenhagen: The Nordic Cochrane Centre.
- Varni, J., Limbers, C., & Burwinkle, T. (2007). Impaired health-related quality of life in children and adolescents with chronic conditions: A comparative analysis of 10 disease clusters and 33 disease categories/severities utilizing the PedsQL 4.0 Generic Core Scales. *Health and Quality of Life Outcomes, 5*, 43.

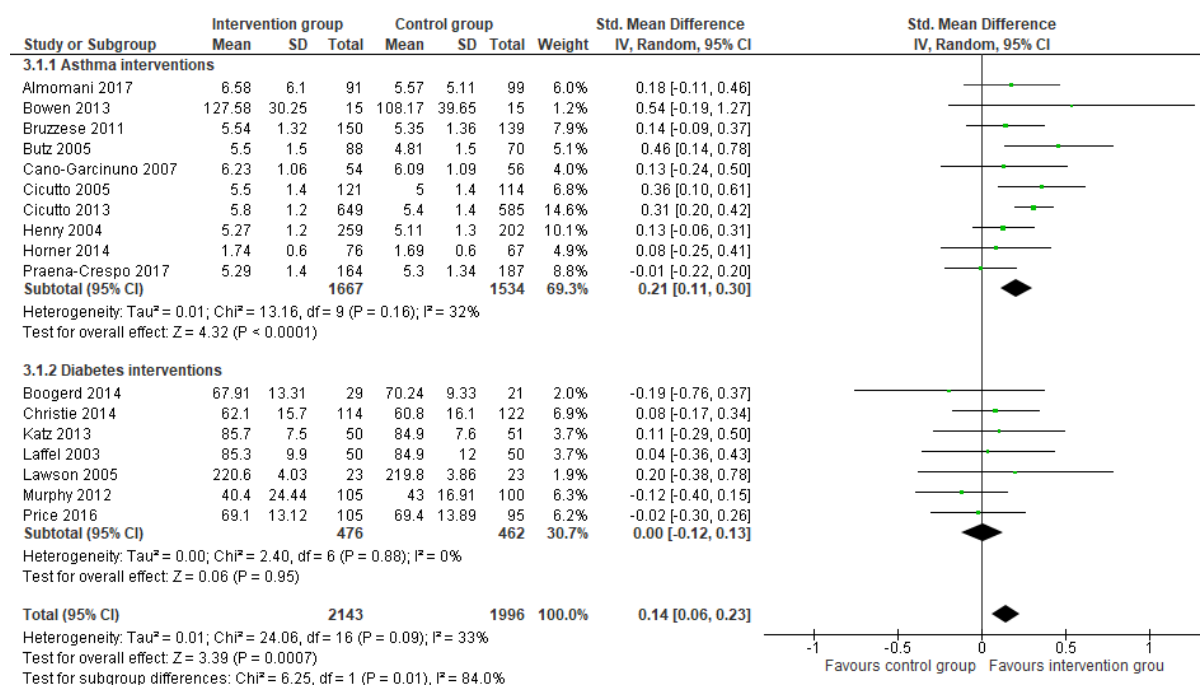


Figure 1 PRISMA 2009 Flow Diagram



Prisma Flow Diagram showing screening and selection of included studies (searches carried out between 16/7/2018 to 12/8/2018)

Figure 2: Summary statistics, effect sizes (Standardised Mean Differences) and forest plot for the included studies, comparing intervention and control groups on Quality of Life outcome.



Diamonds indicate effect sizes for the asthma and diabetes interventions separately and for the pooled effect size. Effect sizes were calculated using post-intervention means and standard deviations. Dots represent the weight of the individual studies. Horizontal error bars represent the 95% confidence intervals for the estimate of effect size for each study.

Table 1: Characteristics of studies included in the meta-analysis

<u>Study</u>	<u>Design</u>	<u>Age in years (Mean)</u>	<u>Setting/ Instructor</u>	<u>Grouping</u>	<u>Mode of delivery and educational content of intervention</u>	<u>Dose/ duration</u>	<u>QoL scale/ reporting</u>
Asthma studies							
Almomani et al., 2017	RCT, uc	7-18 (10)	Clinic Dr	Individual (Ch + Cg)	Demonstrations, explanations, phone call follow-up. Symptoms, triggers, inhaler use, medication	1x 30 min	PAQLQ; dis-sp, SR
Bowen, 2013	RCT, ac	8-12 (9)	Clinic Nurse	Group (Ch)	Structured educational program. Pathophysiology, medications, exacerbations, lifestyle	3x 90 min 3 weeks	PAQLQ, dis-sp, SR
Bruzzese et al., 2011	RCT, wlc	14-16 (15.1)	School Health educator	Group (Ch) Individual	Structured educational program, individual coaching. Pathophysiology, symptoms, medication, triggers, monitoring, lifestyle	3x 45-60 min 8 weeks	PAQLQ, dis-sp, SR
Butz et al., 2005	CIRCT, uc	6-12 (8)	School Health educator	Group (Ch, Cg)	Interactive workshops, demonstrations, discussion. Pathophysiology, medications, symptoms, inhalers, triggers, action plan	2x 120 min	PAQLQ, dis-sp, SR
Cano-Garcinuno et al., 2007	RCT, nd	9-13 (11)	Clinic Dr/nurse	Group (Ch, Cg, Ch+Cg)	Demonstrations, written materials, instruction. Pathophysiology, triggers, medication, inhalers, triggers, exacerbations	3x 45-60 min 6 weeks	PAQLQ, dis-sp, SR
Cicutto et al., 2005	CIRCT, wlc	6-11 (8.6)	School Health educator	Group (Ch)	Structured educational program (RAP). Pathophysiology, triggers, medications/inhalers, symptoms, action plans, lifestyle	6x 60 min 6 weeks	PAQLQ, dis-sp, SR
Cicutto et al., 2013	CIRCT, wlc	6-11 (8.23)	School Health educator	Group (Ch)	Structured educational program (RAP). Pathophysiology, triggers, medications/inhalers, symptoms, action plans, lifestyle	6x 45-60 min 6 weeks	PAQLQ, dis-sp, SR
Henry et al., 2004	CIRCT, wlc	13-14	School Teacher	Group (Ch)	Structured educational program. Pathophysiology, triggers, medications/inhalers, symptoms, lifestyle	3x unsp.	PAQLQ, dis-sp, SR
Horner et al., 2014	CIRCT, ac	7-11 (8.78)	School, home Nurse	Group (Ch), Individual	Demonstrations, instruction, home visit. Symptoms, triggers, pathophysiology, medication, inhalers	16x 15 min 10 weeks	PAQLQ, dis-sp, SR

Praeno-Crespo et al., 2017	CIRCT, wlc	10-12 (10.5)	School Teacher	Group (Ch)	Structured educational program. Pathophysiology, symptoms, triggers, medication, healthy lifestyle, activity	3x 45 min 6 weeks	PAQLQ; dis-sp, SR
Diabetes interventions							
Boogerd et al., 2014	RCT, uc	11-21 (15.23)	Home (comp) Nurse	Individual	On-line interactive website. Individualised treatment overview, monitoring, professional interaction	Variable 9 months	PedsQL-DM; dis-sp, SR
Christie et al., 2014	CIRCT, uc	8-16 (13.1)	Clinic Nurse	Group (Ch + Cg)	Structured educational program. Food, insulin and blood glucose, blood glucose testing, insulin adjustment, lifestyle	4x 120 min 2 days	PedsQL-DM, dis-sp, SR
Katz et al., 2013	RCT, uc	8-16 (12.9)	Clinic RA	Individual (Ch + Cg)	Family teamwork: problem solving, role playing Blood sugar monitoring, hypoglycaemia, weight	4x 30 min 12 months	PedsQL, gen, SR
Laffel et al., 2003	RCT, uc	8-17 (12.1)	Clinic RA	Individual (Ch + Cg)	Family teamwork: responsibility sharing, conflict resolution. Blood glucose monitoring, managing blood sugars	4x 15-20 min 12 months	PedsQL, gen, SR
Lawson et al., 2005	RCT, uc	13-17 (15.2)	Home (tel) Nurse	Individual	Personalised telephone instruction/ discussion. Blood sugar monitoring. Insulin adjustment.	Variable 6 months	DQOLY, dis-sp, SR
Murphy et al., 2012	RCT, uc	11-16 (13.1)	Clinic Nurse	Group (Ch + Cg)	Family teamwork: communication, responsibility sharing. Carbohydrate counting, blood glucose monitoring, insulin adjustment, activity, puberty	6x 90 min 6 months	DQOLY-SF: dis-sp, SR
Price et al., 2016	CIRCT, uc	11-16 (13.8)	Clinic Nurse/ dietician	Group (Ch)	Structured educational program. Carbohydrate counting, insulin adjustment, hypoglycaemia, long term complications	10x unsp. 5 days	PedsQL-DM; dis-sp, SR

RCT: Randomised Controlled Trial, CIRCT: Cluster Randomised Controlled Trial, uc: Usual Care control group, ac: attention control group, wlc: wait list

control group, comp: computer, tel: telephone; RA: Research Assistant, Ch: Child, Cg: Caregiver (parent); unsp: unspecified, min: minutes, PAQLQ:

Pediatric Asthma Quality of Life Questionnaire, PedsQL: Pediatric Quality of Life Inventory, DM: diabetes module, DQOLY: Diabetes Quality of Life for

Youth, SF: short form, dis-sp: disease-specific, gen: generic, SR: self-report. RAP: 'Roaring Adventures of Puff'