WHAT IS THE BEST METHOD OF PATIENT EDUCATION IN PAEDIATRIC PATIENTS WITH CHRONIC HEALTH CONDITIONS?

WHAT IS THE BEST PAEDIATRIC PATIENT EDUCATION SYSTEM AVAILABLE TO BE USED ON A BROAD SPECTRUM OF CHRONIC PHYSICAL HEALTH CONDITIONS THAT CAN HAVE A POSITIVE EFFECT ON THE PATIENT'S QUALITY OF LIFE?

LITERATURE REVIEW

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Date : 22 February 2023

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Summary

Introduction: Patient education is a treatment modality that is essential to physiotherapists and other healthcare professionals alike. However, the topic of paediatric patient education is still relatively unexplored. This literature review looks into finding the best method of patient education for children with chronic health conditions. The search for the best method will be based on an improvement in participant's knowledge and quality of life amongst other outcome measures. The goal of this literature review is to find the best evidence-based patient education program for children with chronic health conditions.

"What is the best method of patient education in paediatric patients with chronic health conditions?"

Methods: For this literature review, the databases PubMed, PEDro and Cochrane were searched for relevant studies. The selected studies were then screened with the inclusion and exclusion criteria followed by a quality analysis using the PEDro scale. Based on the data extracted from the selected studies, the van Tulder's best evidence synthesis (van Tulder M., 2003) was used to analyse the level of evidence provided by each patient education program.

Results: Five studies were selected for use in this literature review. Of the five, three were randomized controlled trials whilst two were clinical trials. There was moderate evidence to support the patient education programs MyATE for asthma and program made for patients with atopic dermatitis. There was limited evidence to support the ModuS patient education program for children with chronic healthcare conditions. Lastly, there was inconclusive evidence to support a modular education program for children with epilepsy.

Conclusion: The outcome of this literature review is inconclusive. This review has helped in further exploring the topic of paediatric patient education and has created an indication for further research. This further research pertains to the domain of broad spectrum patient education programs that can address a variety of chronic health conditions without the need for memorising various patient education programs for specific health conditions.

Introduction

Going to the doctor can prove to be a stressful event for most grown adults, let alone children. According to (J.L., 2016), pediatric patients will visit primary healthcare institutions for an average of 31 times from birth till the age of 21. These visits are simply for general wellness. For children with chronic physical health conditions, going to the doctor or receiving treatment in the hospital is an inevitablity of daily life; making this way above the general average of 31 primary care institution visits. The same study also mentions that children are subjected to psychological trauma which is indicated by anxiety, aggression and anger brought on by a lack of control of their environment. This is something that needs to change in the current paediatric healthcare system.

Patient education is a vital part of changing the paediatric healthcare system for the better. Patient education as defined by (American Academy of Family Physicians , 2000) is the process of influencing patient behaviour and compliance by encouraging changes in knowledge, attitudes as well as developing the skills necessary to maintain or improve health. Effective and efficient patient education has been proven to functionally improve the quality of life of both paediatric patients and their parents – reflected in terms of improved medical adherence and improved knowledge that contributed into a reduction of urgent care visits, hospitalization, visits to the general practitioner and absences from school. (Stenberg U., 2019) Patient education is a duty that is carried on the shoulders of all healthcare professionals involved in direct contact with the patient. This rings true especially for physiotherapists. Patient education has since become a much larger role shouldered by physiotherapists. However, as expressed by (Kelo, 2013) the knowledge gap for this study lies in paediatric patient education not being as widespread or focused on compared to adult patient education.

In recent years, paediatric patient education has improved in leaps and bounds with multiple different patient education systems, modules and guidelines being developed. One of these systems being ModuS. ModuS is a modular self-management patient education programme focusing on common psychosocial aspects of chronic conditions, comprising of generic and disease-specific modules (Ernst G., 2017). While ModuS seems like the answer to all pediatric patient education dilemmas, it does have its limitations. The article with the pilot study was produced in 2017. This makes the system relatively new; with the only other article written on it (Menrath I., 2018) authored by the same group of writers for its initial article. This leaves room for a potential confirmation bias due to both development and evaluation of the system being performed by a single party. This then contributes to the knowledge previously mentioned above. Another limitation of ModuS is ironically one of its main benefits. ModuS focuses on a range of different chronic health conditions as mentioned in (Menrath I., 2018). This could potentially leave the program lacking in specificity for each disease, making it not as effective as other disease-specific programmes. It is also common knowledge that children are very much individuals with varied thought processes and responses to different modalities based on lived experience, cultural differences and a myriad of external factors.

Several studies (Ernst G., 2017), (Menrath I., 2018) have found that patient education can have a profound effect on the quality of life for patients as well as their family members. Studies conducted by (Gurhopur, 2017) and (Dardouri M., 2020) also measured a positive increase in patient knowledge and self-efficacy on top of patient quality of life.

Going off of the information provided above, the population of this literature review will therefore be children between the ages of 3-17.

The intervention used for this literature review would be the patient education model/system.

The outcome of this literature review would be the quality of life and knowledge (if available) of the paediatric patients as well as anyone else involved in their lives – be it family or friends. Many studies measured not just the patient's quality of life but that of their parents as well – this is a logical connection between the two as parent's quality of life does rely substantially on their child's quality of life.

The measurement instruments used for the literature study are stated as above. The instruments utilized will include but are not limited to: Health Related Quality of Life scale (HrQOL) (for both parents and children), Cantril ladder (for both parents and children) , WHO-5 (for parents) and KINDL-R (for children). These measurement instruments will be used as outcome measures of the patient education treatment. A comparison of the participants scores pre- and post-intervention will then be compared to assess the efficacy of the patient education system in question.

This leads to the question formulation of "What is the best paediatric patient education system available to be used on a broad spectrum of chronic physical health conditions that can have a positive effect on the patient's quality of life?". The central concepts that build up the question include the population, intervention and outcome.

The main goal of the research is to find the best evidence based method of paediatric patient education to be used with children. It could either be a program that has been constructed for a singular pediatric chronic health condition with an indication in this review for it to be made into a broad spectrum program or an existing broad spectrum program. This ideal model would be tailored for the child's specific age range and be specific but not restrictive in its protocol; leaving room for improvisation or improvement if needed.

Methods

Study Design

This study is a literature review conducted by a sole researcher. According to (The University of Edinburgh , 2022), a literature review is a piece of academic writing that exhibits knowledge and understanding regarding the academic literature on a specific topic. It also includes a critical evaluation of the material. As the purpose of this research question is to find the best evidence based method of paediatric patient education, some critical evaluation is needed on top of the found material. Therefore, a literature review is the most appropriate study design to answer this research question.

Search Strategy

During the preliminary rounds of researching the topic of this literature review, a search was conducted by a sole researcher on the PubMed, Cochrane library and PEDro databases using a series of search terms in relation to each part of the research question. The terms as well as filters used per database can be seen in Table 1. "AND" and"OR" were used as Boolean operators. "AND" was used between each aspect of the research question (e.g. "population term" AND "intervention term") whilst "OR" was used to link synonyms. No filters were applied to the databases due to the small amount of search results gained from the input of the search terms. The exception to this was PubMed where filters (as seen in Table 1) were applied to further narrow down the search results.

Table 1

Database	Filters	Search string

PubMed	Articles published between 2006-2023, in the English language only, full text available, randomized controlled trial	Search string: (children[MeSH Terms]) AND (patient education[MeSH Terms]) (children[MeSH Terms]) AND (patient education program[MeSH Terms]) ((children[MeSH Terms]) AND (patient education[MeSH Terms])) AND (modus[MeSH Terms])
PEDro	None	"children" AND "patient education"
Cochrane	None	"childhood" OR "child" and "patient education"

Selection Criteria

The inclusion criteria for chosen studies is as follows. (1)The study's population had to be children between the ages of 2-18, (2) the studies had to be performed within the years 2006-2023 in order to ensure that the methods utilised were up to date, (3) appropriate outcome measures for efficacy of the patient education program fell into the domain of either quality of life, patient knowledge or self-efficacy. (5) the intervention had to be a patient education program, (6) studies that were written in or translated into the English language, (8) the participants had to have a chronic health condition and (7) studies that were clinical trials or randomised controlled trials.

The exclusion criteria involved (1) participants that had a chronic mental health condition/behavioural issues/conditions that severely affected cognitive ability, (2) studies with no full text available, (3) animal studies, (4) studies that focused solely on the education of parents with no involvement of the paediatric patients themselves.

Methodological Quality Analysis

The critical appraisal tool selected for this study was the PEDro scale (Matos A.P., 2020). The PEDro scale has been widely lauded for its use in assessing the quality of clinical trials as it has been found to be a valid and reliable instrument (Cashin A.G., 2020). The PEDro scale bases itself off a checklist of 11 items scored as yes or no questions in regard to the internal validity and the information provided. Item number 1 is not included in the overall score of 10 as it relates to external validity or generalizability of the sample. The same article by (Cashin A.G., 2020) reports that total PEDro scores of 0-3 are considered 'poor', 4-5 as 'fair', 6-8 as 'good', and 9-10 as 'excellent'. Table 2 shows the PEDro score of each article alongside the breakdown of the scoring sheet. (Verhagen AP, 1998). This scoring was performed by the researcher for this literature review.

Data Extraction

Apart from assessing the methodological quality of the selected studies, further data was extracted. The data extracted consisted of the authors, the published year, the participants characteristics, the population type, type of patient education programme used, outcome as well as outcome measurement, and the type of study. Details of the data extraction can be found in Table 3.

Table 3

Author and year	Patient characteristics	Type of patient education program	Relevant type of measurement instrument used	Outcome Measured	Type of study
Gurhopur et al (2017)	100 participants aged 7-18 years. The population consisted of children with epilepsy.	Modular epilepsy-specific education program	Epilepsy Knowledge Test for Children, The Seizure Self-efficacy scale for children, Quality of Life in Epilepsy Inventory	Knowledge, Self-efficacy, Quality of life	Randomized Controlled Trial
Ernst et al (2017)	491 participants aged 6-17 years. The population consisted of children with asthma.	ModuS	Modified questionnaire by Schulte im Walde, Disabkids Chronic Generic Measure (DCGM-37), Cantril ladder	Asthma knowledge, Health-related quality of life	Clinical trial
Dardouri et al (2019)	82 participants aged 7-17 years. The population consisted of children with asthma.	My Asthma Therapeutic Education (MyATE)	Pediatric Asthma Quality of life Questionnaire	Quality of life	Randomized Controlled Trial
Menrath et al (2018)	398 participants aged 7-17 years. The population consisted of children with chronic health conditions	ModuS	Disabkids Chronic Generic Measure (DCGM-37), Cantril ladder, self constructed knowledge questionnaire	Health-related quality of life, knowledge	Clinical Trial
Yuan et al (2017)	580 participants aged 2-14 years. The	Lecture program	Children's dermatology quality of life index (CDLQI)	Quality of life, knowledge	Randomized Controlled Trial

	population consisted of children with atopic dermatitis.		and Infants Dermatitis Quality of Life Index (IDQOL), questionnaire on patient knowledge (self constructed)		

Data Analysis

The method of data analysis selected for this study is best evidence synthesis. According to (R.E., 1986) the method of best evidence synthesis 'combines the quantification of effect sizes and systematic study selection procedures of quantitative syntheses with the attention to individual studies and methodological and substantive issues typical of the best narrative reviews'. The best evidence synthesis centres around finding the best evidence in a particular field by utilizing the internal and external validity as well as a well-defined and defended inclusion criteria and effect size data in a given study. According to (R.E., 1986), there is no set format for a best evidence synthesis and it is instead up to the researcher to define the reflection of the best evidence synthesis by taking into account the field of the research as well as other relevant factors. It was then decided that van Tulder's levels of evidence would be used for this literature review (van Tulder M., 2003).

In this literature review, the best evidence synthesis would be based on the effect size, calculated with (Social Science Statistics , n.d.), the p value between the intervention and control groups as well as the PEDro score of each article. Effect size can be interpreted as small (d = 0.2), medium (d= 0.5) and large (d = 0.8) (D., 2013) .

For the effect size within groups in Table 6 (found in Appendix), Cohen's D was used as the groups had similar standard deviations and the same sample size. As for the effect size between groups in Table 7 (found in Appendix), Hedge's g was used to measure the effect size due to the difference in sample size. (Social Science Statistics , n.d.)

Results

Study Selection

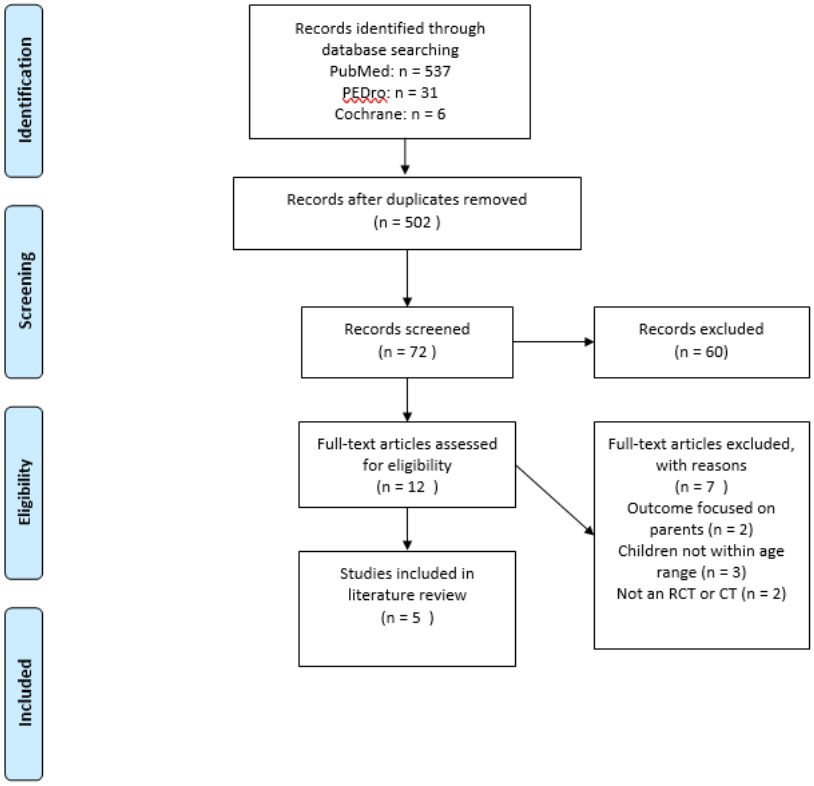
For this literature review, 5 articles were selected using the selection process as detailed in the Methods portion of this literature review. Out of the 5 studies, 3 were randomized controlled trials (Gurhoper F.D.T., 2017), (Dardouri M., 2020), (Yuan L., 2017), and the remaining 2 studies were clinical trials (Ernst G., 2017), (Menrath I., 2018).

First, the databases PubMed, PEDro and Cochrane were searched for suitable articles. The articles were then screened with the inclusion and exclusion criteria. Duplicates, articles where full text was unavailable, and articles that were not in English were also removed. Then, the remaining articles were assessed for eligibility through the reading of the full text. Upon the reading of the full text, some articles were discarded due to not meeting eligibility criteria. The articles that remain are the articles selected for inclusion in the literature review.

Further information in regard to the number of articles found and the search process can be found in Figure 1 which is a PRISMA flow diagram (Moher D., 2009). Information about each selected

article's data extracted was made into a table (Table 3). This table included the names of the authors, year of publication, the participant characteristics, the type of paediatric patient education program used, the study design, the outcome measured and the relevant measurement instrument used.

FIGURE 1



RCT: randomised controlled trial, CT: clinical trial

Population Characteristics

The total population of participants in this literature review amount to 1651 participants (n = 1651) across the five studies. This number accounts only for the number of children participating in this study. Despite some of the selected studies involving parents in the population as well, the parents were omitted from the total number of participants as this literature review's focus is on the patient education provided to the children and not the parents (refer to inclusion and exclusion criteria in Methods). The children were all aged between 2-18 years of age. The selected studies looked at a varied range of chronic conditions in the population with two studies on asthma (Dardouri M., 2020) (Ernst G., 2017), one on epilepsy (Gurhoper F.D.T., 2017), one on atopic dermatitis (Yuan L., 2017) and one on common childhood chronic conditions which consisted of: Chronic inflammatory bowel disease (IBD), Cystic fibrosis (CF), Phenylketonuria (PKU), Nephrotic syndrome (NS), Urinary incontinence (UI), Chronic functional abdominal pain (CFAP) and Primary immunodeficiency disease (PID) (Menrath I., 2018).

Interventions

The studies looked at a host of interventions with the common denominator being that all interventions were a paediatric patient education program for a chronic paediatric health condition. (Gurhoper F.D.T., 2017) utilised a modular education program for children with epilepsy and their

families, (Ernst G., 2017) developed a modular education program for children with asthma with the intention of using this education program for children with chronic conditions, (Dardouri M., 2020) utilised an education program for children with asthma, (Menrath I., 2018) trialled a modular education program that was targeted towards children with chronic health conditions and (Yuan L., 2017) focused their education program on children with atopic dermatitis. Further information regarding the interventions used by each study can be found under Table 4 in the Appendix.

As for control groups, the study by (Yuan L., 2017) did not specify what alternative treatment the control group received instead of the intervention. It was also unclear whether or not the control group received the intervention at the end of the study. As for the study by (Dardouri M., 2020) the control group received a the usual standard of patient education for children with asthma as opposed to the intervention program. This control group was trained with the intervention (MyATE) upon completion of the study. In the study conducted by (Gurhoper F.D.T., 2017), the control group was not given any training throughout the study period despite being measured with the same measurement instruments as the intervention group. They were however trained with the intervention upon completion of the study. The study by (Ernst G., 2017) had a control group that was trained using conventional asthma education instead of the intervention program (ModuS). As for studies without a control group, the study by (Menrath I., 2018) also did not include a control group mainly due to the sample size already being small as they focused their study on chronic childhood conditions – some that were uncommon and difficult to recruit participants for.

Outcomes

The selected studies used a myriad of outcome measures – some which overlapped. All data regarding outcome measures was taken from the children's score and not that of the parents.

(Gurhoper F.D.T., 2017)'s outcome measures were disease specific knowledge measured by a knowledge test, self-efficacy measured by a self-reported scale and quality of life measured with a questionnaire. (Ernst G., 2017)'s and (Menrath I., 2018)'s outcome measures were also knowledge measured by a knowledge test, health-related quality of life measured by a generic measuring tool and life satisfaction measured with a self-reported visual scale. The study by (Dardouri M., 2020) had two outcome measures – quality of life measured with a questionnaire and pulmonary function using spirometry. Finally, the study by (Yuan L., 2017)'s outcome measure was quality of life measured using a quality of life index.

The full details of the outcome measures used for each study as well as what measurement instruments were used for each measure can be found in the table below in the Appendix under the heading Table 5. It should be noted that all studies (with the exception of (Ernst G., 2017) and (Menrath I., 2018)) utilized different measurement instruments for their overlapping outcome measures.

Results for Outcome Measures

Below the results for each outcome measure mentioned above are presented. An overview of the outcome measures can be found in Table 8 of the report. More detailed tables detailing the results within and between groups can be found in the Appendix under Tables 6 and 7.

Disease-Specific Knowledge

The results from each study are as follows. In the study by (Gurhoper F.D.T., 2017), there was a reported increase in the mean scores for knowledge level in the intervention group post program and during the follow-up ($p < 0.001$). The mean scores for the control group for knowledge level

were low and did not have a significant change in the follow-ups. ($p < 0.001$). The results from this study did not have sufficient information to tabulate the effect size between the intervention and control groups.

As for the study conducted by (Ernst G., 2017), the children who participated in the ModuS program experienced an increase in their asthma knowledge from 43.5 (SD: 19.8) to 78.5 (12.6). This result was statistically significant with a p value of <0.01. This was similar to the knowledge increase of children who received conventional asthma education (CAE) 44.8 (SD: 18.4) to 75.9 (SD: 13.3) with a p value of $p<0.001$. Between the groups (intervention and control) there was a small effect size of 0.2 (P., 2023) and a statistically significant p value of 0.04.

The study conducted by (Menrath I., 2018) showed positive and statistically significant outcomes in disease-specific knowledge for the ModuS program in children with chronic health conditions from scores of 50.8 (SD 22.2) at baseline to 75.3 (SD 18.6) 6 weeks post program as well as children with asthma from scores of 42.8 (SD 19.4) to 78.4 (SD 12.6), both with p values of $p <0.001$. Between the control and intervention groups there was a small effect size of 0.2 (rounded up from 0.199) with no calculated p value between the groups.

Quality of Life (Health-related Quality of Life) and Life Satisfaction

In the study performed by (Gurhoper F.D.T., 2017), the quality of life of participants in the intervention group increased significantly compared to the control group with a p value of $p < 0.001$. The results from this study did not have sufficient information to tabulate the effect size between the intervention and control groups.

(Ernst G., 2017) reported that children in the intervention group (ModuS) had a significant increase in their health related quality of life score from 80.6 (SD 12.8) to 82.6 (SD 13.4) at baseline and 6 weeks post-programme respectively. This was also statistically significant with a p value of $p = 0.003$. The children who received conventional asthma education (CAE) received scores of 80.0 (SD 14.3) at baseline and 82.9 (SD 12.3) 6 weeks post program. This result was also statistically significant with a p value of $p < 0.001$. The results for satisfaction with life in the ModuS group had an increase from 7.7 (SD: 1.5) to 8.0 (SD: 2.6) with a p value of no statistical significance (0.144). The results for the CAE group for life satisfaction saw slight change in standard deviation from 7.9 (SD: 2.9) to 7.9 (SD: 3.5) from baseline to 6 weeks post intervention. This was not statistically significant with a p value of 0.436. There was an insignificant effect size of 0.02 and 0.03 between the ModuS and CAE groups for health-related quality of life and satisfaction with life respectively. The p values between the ModuS group and CAE group were not statistically significant at 0.3 and 0.7 respectively.

(Dardouri M., 2020) reported that the quality of life questionnaire total and subscale scores (all $p < 0.001$) in the intervention group (MyATE) at baseline and follow-up were significantly and positively different. Meanwhile, in the control group (IEAS) the total score of the quality of life questionnaire showed a positive significance within time with a ($p = 0.02$). Between the intervention (MyATE) group and control (IEAS), a large effect size (0.9) and a statistically significant p value (0.001) were found.

(Menrath I., 2018) reported that the participants with chronic health conditions scored a 75.5 (SD 11.8) at baseline and a 77.2 (SD 13.0) 6 weeks post-programme for their health-related quality of life questionnaire ($p = 0.020$). For the life satisfaction questionnaire, the participants with chronic health conditions went from a score at 7.4 (SD 1.9) at baseline to 7.5 (SD 1.7) 6 weeks post program ($p = 0.432$). As for the children in the asthma group, the participants had a baseline of 81.2 (SD 12.2) and a score of 82.8 (SD 12.7) 6 weeks post program. This was statistically significant with a score of $p = 0.034$. As for life satisfaction, the children in the asthma group had a baseline score of 8.1 (SD 1.6)

and a score of 8.3 (SD 1.7) 6 weeks post program. However, these results were not statistically significant with a p value of p = 0.153. As for the difference between the chronic health conditions and asthma group, there was a medium effect size of 0.4 and 0.5 for health-related quality of life and life satisfaction respectively. There were no statistically significant p values between the groups for life satisfaction (p=0.554) and health-related quality of life (p=0.479)

According to the study performed by (Yuan L., 2017), at 6 months post-program, the quality of life in children aged 2-4 years of age was significantly greater in the intervention group wherein the mean IDQOL score fell from 10.3 ± 5.5 at baseline to 4.2 ± 3.5, compared to the control group, wherein the mean IDQOL fell from 10.1 ± 5.2 at baseline to 5.1 ± 4.2 (p = 0.030). For the quality of life in infants, there was a small effect size of 0.2 between the intervention and control groups. The quality of life for children also presented with a small effect size of 0.2 (rounded up from 0.166). There was no p value calculated for between the intervention and control groups in quality of life for infants and children.

Other Outcome Measures

Two other outcome measures from the selected studies that have not been mentioned above are self-efficacy from the article by (Gurhoper F.D.T., 2017) and pulmonary function (Dardouri M., 2020).

Due to these outcome measures not having any overlap with the other studies, they were excluded from tabulation in the results table. This will be elaborated further in the discussion section of this literature review.

Table 8 (Overview of Results)

Study, Year of publication, Study design	Authors	Participants	Intervention	Control	Outcome measures	Results	PEDro Score
The effect of a modular education program for children with epilepsy and their parents on disease management (2017), RCT	Gurhoper, Dalgic	N/A	N/A	N/A	Knowledge Self-efficacy Quality of life	Statistical significance: 0.001 ES between groups: N/A	6
Development and evaluation of a generic education program for chronic diseases in childhood (2017), CT	Ernst, Menrath, Lange, Eisemann, Staab, Thyen, Szczepanski, on behalf of ModuS study group	Mod: 166 CAE: 158	78.5 (SD: 12.6)	75.9 (SD: 13.3)	Knowledge	Statistical significance: 0.044 ES between groups: 0.201	5
		Mod: 182 CAE: 149	82.6 (SD: 13.4)	82.9 (SD: 12.3)	Health-related quality of life	Statistical significance: 0.479	

						ES between groups: 0.023	
		Mod: 185 CAE: 144	8.0 (SD: 2.8)	7.9 (SD: 3.5)	Satisfaction with life	Statistical significance: 0.712 ES between groups: 0.032	
Effect of family empowerment education on pulmonary function and quality of life of children with asthma and their parents in Tunisia: A randomized controlled trial (2020), RCT	Dardouri, Sahli, Ajmi, Mtiraoui, Bouguila, Zedini, Mallouli	MyATE: 34 IEAS: 34	6.29 (SD: 0.78)	5.39 (SD: 1.10)	Quality of life	Statistical significance: 0.001 ES between groups: 0.944	5
Evaluation of a generic patient education program in children with different chronic conditions (2018), CT	Menrath, Ernst, Lange, Eisemann, Szczepanski, Staab, Degner, Thyhen, on behalf of ModuS study group	PLCC: 125 Ast: 156	75.3 (SD: 18.6)	78.4 (SD: 12.60.199)	Knowledge	Statistical significance: N/A ES between groups: 0.199	4
		PLCC: 130 Ast: 171	77.2 (SD: 13.0)	82.8 (SD: 12.7)	Health-related quality of life	Statistical significance: 0.479 ES between groups: 0.436	
		PLCC: 127 Ast: 170	7.5 (SD:1.7)	8.3 (SD: 1.7)	Life satisfaction	Statistical significance: 0.554 ES between	

						groups: 0.471	
Therapeutic patient education in children with moderate to severe atopic dermatitis: A multicenter randomized controlled trial in China (2017), RCT	Yuan, Jing, Chun, Feng, Hua, Ping, Yan, Feng, Lin	Int: 178 Con: 151	4.23 (Sd: 3.51)	5.08 (SD: 4.25)	Quality of life (infants)	Statistical significance: N/A ES between groups: 0.220	6
		Int: 96 Con: 83	4.71 (SD: 4.32)	5.43 (SD: 4.36)	Quality of life (children)	Statistical significance: N/A ES between groups: 0.166	

Int: Intervention, Con: Control, Mod: ModuS, CAE: Conventional Asthma Education, MyATE: My Asthma Therapeutic Education, IEAS: Individual Education by Asthma Specialist, PLCC: Population with Less Common Chronic Conditions, Ast: Population with Asthma

Best Evidence Synthesis

The method used for assessing the quality of the articles for this study is best evidence synthesis. The factors that will play a role in performing the aforementioned synthesis are PEDro score, effect size between control and intervention groups for the study as well as the p values between both groups.

According to (van Tulder M., 2003), there are four levels of evidence, each with increasing strength. Strong evidence, moderate evidence, limited evidence and inconclusive evidence. A diagram of the criteria required to fulfil each level of evidence can be found in the Appendix under Figure 2.

In order to construct the best evidence synthesis, out of the five studies included in this literature review: two studies were rated of high quality (Gurhoper F.D.T., 2017) (Yuan L., 2017), and the remaining three were rated of medium quality (Dardouri M., 2020) (Ernst G., 2017) (Menrath I., 2018).

There was limited evidence that ModuS patient education program managed to improve the knowledge, quality of life and life satisfaction of the participants in both studies (Ernst G., 2017) (Menrath I., 2018).

There was moderate evidence that MyATE asthma education program positively affected the quality of life of the study's participants (Dardouri M., 2020).

There was also moderate evidence that the education program conducted by (Yuan L., 2017) on children and infants with atopic dermatitis had a positive effect on their quality of life.

Finally, there was inconclusive evidence from (Gurhoper F.D.T., 2017) that the modular education program for children with epilepsy improved the quality of life, self-efficacy and knowledge of the children.

Discussion

This literature review was performed to find the best method of patient education for children with chronic health conditions. Patient education is found to have a positive effect on disease specific knowledge (Chomik S., 2014), quality of life (Miraj S.S., 2015) and self-efficacy (Peters M., 2019).

This review showed that there was moderate evidence (Dardouri M., 2020) and atopic dermatitis education program (Yuan L., 2017) improving the quality of life of their respective participants. ModuS, which was the only program that had been developed for a broad spectrum of chronic health conditions, presented with limited evidence on the van Tulder level of evidence scale (van Tulder M., 2003). Lastly, there was inconclusive evidence in the study performed by (Gurhopur, 2017) for children with epilepsy.

Whilst all studies included quality of life as an outcome measure, three included disease specific knowledge (Gurhoper F.D.T., 2017) (Ernst G., 2017) (Menrath I., 2018), one included self-efficacy (Gurhoper F.D.T., 2017) and one included pulmonary function (Dardouri M., 2020). Disease-specific knowledge and quality of life were included in the tabulation of the results but pulmonary function was not taken into account. During the results tabulation, pulmonary function was only included in one study (Dardouri M., 2020) and including it into the general results tabulation would affect the homogeneity of the outcome measures chosen as well as have a lack of other outcome measures for proper comparison of results to take place. There was also another outcome measure mentioned – 'satisfaction with life' in the articles by (Ernst G., 2017) and (Menrath I., 2018). As the definition of 'satisfaction with life' shared similarities with 'health-related quality of life' and shared a significant correlation (Yildirim Y., 2013), it was included in the results tabulation.

It can be concluded from the results of this study that there the search for the best method of paediatric patient education for chronic health conditions is inconclusive or has limited evidence. This can be attributed to the very broad scope of the research question (the range of chronic health conditions) and the difference in patient education programs specific to each condition. This can also be attributed to the limited studies included in this review due to the lack of research on the topic of paediatric patient education.

The only studies in this literature review that actually strived to answer the research question were based on ModuS – a generic patient education program currently being developed in order to be utilized on children with different chronic conditions – with the program's material following the same modular approach with different material based on the condition afflicting the child (Ernst G., 2017) (Menrath I., 2018). ModuS is the only method of patient education that covers multiple chronic health conditions in children. Unfortunately, due to limited evidence, no statistically significant results and small effect sizes, no clear answer to the research question of this literature review can be derived from ModuS.

However, it can also be argued that these studies were not randomized controlled trials but clinical trials instead. In the study by (Ernst G., 2017), ModuS was used as an asthma education program and compared against conventional asthma education. This was done on two groups with the ModuS group being seen as the 'intervention' group and the conventional asthma education (CAE) group as the 'control' in the results. Both groups had similar results which may explain the poor effect size and lack of statistical significance between the groups. Within each group however there was a large effect sizes for knowledge and a small effect size for health-related quality of. This shows a similarity in results for both methods of education which can be argued that ModuS has the same positive effect that CAE does on paediatric asthma patients. ModuS was also further tested on children with a

variety of chronic health conditions in the study by (Menrath I., 2018). It was then compared with children who received ModuS for asthma only. This showed similarities in results for the outcome measures knowledge. The results for health-related quality of life and life satisfaction were not as promising and did not show significant effect. It can be said that the results for both chronic conditions and asthma were homogenous.

As for the other disease-specific patient education programs, it can be said that the programs developed and trialled by (Dardouri M., 2020) and (Yuan L., 2017) for asthma and atopic dermatitis respectively have the highest level of evidence for this literature review (moderate level of evidence). It can be said that these two studies had the most evidence based study design (randomized controlled trial) and consistent findings that were statistically significant. Of the two, it was found that (Dardouri M., 2020) presented with the best results thus far with a large effect size of 0.944 and a statistically significant p value of 0.001. It was also rated with a good PEDro score of 6/10. Overall for this review, MyATE has proven to be the best patient education program from a results point of view. However, it cannot be assumed that MyATE (the program developed by (Dardouri M., 2020)) is the best method of patient education for chronic conditions as it only focused on individuals with asthma and not chronic conditions in general.

When examining the populations included in this literature review, the outcome measures had the potential to be affected by the difference in chronic conditions experienced by each population included in the study. The study by (Gurhoper F.D.T., 2017) involved children with epilepsy, the studies by (Ernst G., 2017) and (Dardouri M., 2020) were on children with asthma, the study by (Yuan L., 2017) centred around children with atopic dermatitis and the study by (Menrath I., 2018) included children with different chronic conditions. This affects the homogeneity of the results of this literature review.

When looking at other research performed on the topic of methods of paediatric patient education, there was the unexplored avenue of web-based or digital patient education. As the world continues to evolve at a rapid pace in technological advancement, it was unsurprising to uncover that patient education has been digitised in some studies. A study performed by (Runge C., 2006) used an Internet-based patient education program on asthmatic children with the results showing a reduction in emergency room visits for the children. Another aspect of patient education found was game/music-based education. A study by (Sharififard N., 2020) centred around the development and trial of a music- and game-based oral health education for visually impaired school children with positive results indicating the efficacy of the patient education program.

One aspect that was also often touched on was patient education solely for the parents of infants with chronic conditions. A study by (Chen H., 2019) focused on the patient education of the parents of infants with congenital cataract with positive results on outcome measures. The study used parental anxiety, knowledge and satisfaction as outcome measures. Whilst knowledge and satisfaction are common parameters for measuring patient education in the studies found for this review, parental anxiety was not. Parental anxiety is associated with a low outcome of quality of life in children (Jones C., 2016). This leads to the question on what can be done for parents of infants (who are not old enough for patient education themselves) with congenital chronic conditions to prepare them for educating their children on their condition as they grow and develop. This could potentially aid healthcare professionals when treating these children as they would already have a strong base of patient education from childhood due to the prior education of their parents.

This literature review has multiple strengths and weaknesses. A main strength of this review was that it further explored a relatively untouched topic of paediatric patient education for children with

chronic health conditions. This review is a starting point of raising awareness on the importance of developing a strong, evidence-based protocol for chronically ill children.

A main strength of the review was that the articles had at least one outcome measure in common (quality of life) with other similar overlapping outcome measures (knowledge, life satisfaction). The articles also provided enough data for the calculation of the effect sizes within and between groups (with the exception of (Gurhoper F.D.T., 2017)). It is also a strength that all articles were either clinical trials or randomized controlled trials with moderate levels of evidence on the PEDro scale (4/10 being the lowest (Menrath I., 2018).

Another strength of this review was the broad research question. It left the topic very open-ended with room to add multiple different programs for a myriad of conditions without being restrictive to a certain condition in particular. As the world of physiotherapy often presents patients with multiple conditions, that can make using multiple different patient education programs for each specific condition difficult.

The weakness to the research question lies in the inability to provide a direct answer to the research question as it is too presumptuous to say for certain that a patient education program meant for a specific chronic condition can be modified and used just as successfully with other chronic conditions as well.

A limitation of this review was outlier in terms of outcome measures chosen by some of the studies chosen for this review. The study by (Dardouri M., 2020) had the spirometry values of asthmatic paediatric patients as an outcome measure. This outcome measure had to be excluded from the results as it was too specific to asthma as a chronic condition and did not have any overlaps with the other studies chosen.

Another limitation was that the PEDro scores and best evidence synthesis were conducted by the sole researcher for this review. This leaves room for a potential confirmation bias due to the absence of a third party to confirm the scores and levels of evidence for the review.

Conclusion

To conclude this literature review, it can be said that there is no exact answer to the research question due to inconclusive evidence. The aspect of the research question being too broad and there only being one broad-spectrum patient education program and the others being specific education programs has also had an effect on the outcome of this review.

There is definitely an indication for further research and development of broad spectrum patient education programs that can allow ease of use for physiotherapists or other relevant health professionals who encounter a variety of chronic health conditions in children during treatment. Utilising different patient education programs or having to undergo training and certification for so many different programs specific to each disease is unrealistic for physiotherapists and other healthcare professionals as there are so many similarities in material for patient education programs for chronic conditions in childhood.

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Appendix

Appendix 1: Table 2: PEDro scores for all articles included in the study

PEDro Criteria	Gurhoper et al	Ernst et al	Dardouri et al	Menrath et al	Yuan et al

1. Eligibility criteria were specified (not included in final score)	+	+	+	+	+
2. Subjects were randomly allocated to groups (in a crossover study, subjects were randomly allocated an order in which treatments were received)	+	+	+	-	+
3. Allocations was concealed	+	+	+	-	-
4. The groups were similar at baseline regarding the most important prognostic indicators	+	-	+	-	+
5. There was blinding of all subjects	-	-	-	-	-
6. There was blinding of all therapists who administered the therapy	-	-	-	-	-
7. There was blinding of all assessors who measured at least one key outcome	-	-	-	-	-
8. Measures of at least one	-	-	+	+	+

key outcome were obtained from more than 85% of the subjects initially allocated to groups					
9. Of all subjects for whom outcome measures were available received the treatment or control condition as allocated or, where this was not the case, data for at least one key outcome was analysed by "intention to treat"	+	+	+	+	+
10. The results of between-group statistical comparisons are reported for at least one key outcome	+	+	+	+	+
11. The study provides both point measures and measures of variabliity for at least one key outcome	+	+	+	+	+
12. Final score	6/10	5/10	5/10	4/10	6/10

Appendix 2: Table 4: Interventions used for each study

Study (author)	Intervention
Gurhoper et al	The Modular Education Program for Children with Epilepsy and Their Parents. Modules (For children): Module 1: Knowledge About Epilepsy Module 2: Epilepsy and I Module 3: Seizure Management Module 4: Epilepsy and Social life How the program was conducted: The education program was taught to children and parents one-to-one in a quiet environment. The modular education program was taught on weekdays (2-3), spanning a total duration of 16 hours. Program conducted by: Researchers Materials: - Slides - Videos - Brochures - Flipcharts - Guide to Living with Epilepsy - Antiepileptic drugs
Ernst et al	ModuS: Modular education program for chronic diseases in childhood Modules: 0. Organization and Preparation 1. Introduction and getting acquainted (45 min) 2. Explanation of the disease, its treatment and prognosis (45-90 min depending on disease) 3. Competencies and motivation for basic therapy (90-360 min depending on disease) 4. Competencies for preventing or managing acute crises (45-135 min depending on disease) 5. Coping with disease in family life, in school and in social activities (180-270 min) 6. Completion and maintenance (45-90 min)

	How the program was conducted: The program can either be taught in weekly sessions or as a block over several days. There are variances in the implementation of each module depending on the age range of the children (6-12 years and 13-17 years). Program conducted by: - Psychologist (Modules 1,5 and 6) - Paediatrician (Modules 1, 2,3,4 and 6) - Physiotherapist (Module 3) - Dietician/nurse (Module 3) Materials: The full detailing of the materials required for each module can be found on ((KomPaS), 2020)
Dardouri et al	My Asthma Therapeutic Education (MyATE) Content covered: - Basic information about asthma - Recognition and response to asthma symptoms and asthma exacerbations - Use of asthma medication and inhalation techniques - Identification and control of asthma triggers - Effective ways to communicate with healthcare providers How the program was conducted: The program took place in the waiting room of the paediatric outpatient clinic of a university hospital. The program comprised of four group sessions divided into two days over a period of eight weeks. Program conducted by: Researchers with consultation of paediatrician-pulmonologist Materials: - Asthma booklet - Action plan for asthma crisis based on the Global Initiative for Asthma guidelines (Global Initiative for Asthma , 2019) in the native language of the participants

Menrath et al	ModuS: Modular education program for chronic diseases in childhood Modules: 7. Organization and Preparation 8. Introduction and getting acquainted (45 min) 9. Explanation of the disease, its treatment and prognosis (45-90 min depending on disease) 10. Competencies and motivation for basic therapy (90-360 min depending on disease) 11. Competencies for preventing or managing acute crises (45-135 min depending on disease) 12. Coping with disease in family life, in school and in social activities (180-270 min) 13. Completion and maintenance (45-90 min) How the program was conducted: The program was conducted mostly over two consecutive days in 24 institutions in Germany. Program conducted by: - Psychologist (Modules 1,5 and 6) - Paediatrician (Modules 1, 2,3,4 and 6) - Physiotherapist (Module 3) - Dietician/nurse (Module 3) Materials: The full detailing of the materials required for each module can be found on ((KomPaS), 2020)
Yuan et al	Researcher-made intervention program Content: 1. Long-term treatment and management of Atopic Dermatitis 2. Food allergy and Atopic Dermatitis 3. How to increase the family happiness index of patients using psychological interventions 4. Skin care 5. The use of emollients for Atopic Dermatitis How the program was conducted:

	The program was conducted over a span of a month with four once-weekly group sessions of 30-40 participants. The program was delivered in the form of a 2 hour lecture each session. Program conducted by: - Paediatric dermatologists (2) - Psychologist - Advanced practice nurse in dermatology Materials: - Video recordings of each lecture - Related printed materials of each lecture - Therapy and diet recommendations for each patient based on individual disease severity with no restrictions in study protocol

Appendix 3: Table 5: Outcome measures for each study

Study	Outcome measures	Measurement Instrument for Outcome Measure (*indicated with matching number*)	Frequency of Measurements
Gurhoper et al	1. Knowledge regarding epilepsy (disease specific knowledge) 2. Seizure self-efficacy 3. Quality of life	1. The Epilepsy Knowledge Test for Children (EKTC) 2. The Seizure Self-efficacy Scale for Children (SSES-C) 3. The Quality of Life in Epilepsy Inventory (QOLIE-48)	- All participants were measured before the start of the intervention. - All participants were measured 1 month and then 3 months post-program during follow-ups
Ernst et al	1. Asthma knowledge 2. Health-related quality of life 3. Satisfaction with life	1. Slightly modified version of questionnaire developed by (Walde, 2000)	- All participants were measured before the program

		2. Disabkids Chronic Generic Measure (DCGM-37) (self-reported version) 3. Cantril ladder	started (baseline) - All participants were measured 6 weeks post-program
Dardouri et al	1. Quality of life 2. Pulmonary function	1. Paediatric Asthma Quality of Life Questionnaire (PAQLQ) 2. Spirometry testing with ZAN 100	- All participants were measured at baseline at the start of the program - All participants were measured at a 12 month follow-up
Menrath et al	1. Asthma knowledge 2. Health-related quality of life 3. Satisfaction with life	1. Slightly modified version of questionnaire developed by (Walde, 2000) 2. Disabkids Chronic Generic Measure (DCGM-37) (self-reported version) 3. Cantril ladder	- All participants were measured before the program started (baseline) - All participants were measured 6 weeks post-program
Yuan et al	1. Quality of life	1a. Children's Dermatology Life Quality Index (CDLQI) (ages 5-16 years) 1b. Infant's Dermatitis Quality of Life Index (IDQOL) (ages 2-4 years)	- All participants were measured at the start of the program (baseline) - Participants were measured post-program once at the 3-month mark and once at the

			6-month mark

Appendix 4: Table 6: Within group results

Study	Outcome Measure	Population	Baseline	Follow-up	Mean difference within group	Statistical significance (p value)	Effect size (Cohen's d)
Gurhoper et al	Knowledge	N/A	N/A	N/A	N/A	N/A	N/A
	Quality of life	N/A	N/A	N/A	N/A	N/A	N/A
Ernst et al	Knowledge	Mod: 166 CAE: 158	Mod: 43.8 (SD: 19.8) CAE: 44.8 (SD: 18.4)	Mod: 78.5 (SD: 12.6) CAE: 75.9 (SD: 13.3)	Mod: 34.7 CAE: 31.1	Mod: p < 0.001 CAE: p < 0.001	Mod: 2.09 CAE: 1.94
	Health-related quality of life	Mod: 182 CAE: 149	Mod: 80.6 (SD: 12.8) CAE: 80.0 (SD: 14.3)	Mod: 82.6 (SD: 13.4) CAE: 82.9 (SD: 12.3)	Mod: 2 CAE: 2.9	Mod: p = 0.003 CAE: p < 0.001	Mod: 0.153 CAE: 0.217
	Satisfaction with life	Mod: 185 CAE: 144	Mod: 7.7 (SD: 1.5) CAE: 7.9 (SD: 2.9)	Mod: 8.0 (SD: 2.6) CAE: 7.9 (SD: 3.5)	Mod: 0.3 CAE: 0	Mod: p = 0.144 CAE: p = 0.436	Mod: 0.141 CAE: 0
Dardouri et al	Quality of life	MyATE: 34 IEAS: 34	MyATE: 4.50 (SD: 1.23) IEAS: 4.87 (SD: 1.26)	MyATE: 6.26 (SD: 0.78) IEAS: 5.39 (SD: 1.10)	MyATE: 1.76 IEAS: 0.52	MyATE: p= 0.001 IEAS: p = 0.02	MyATE: 1.710 IEAS: 0.440
Menrath et al	Knowledge	PLCC: 125 Ast: 156	PLCC: 50.8 (SD: 22.2) Ast: 42.8 (SD: 19.4)	PLCC: 75.3 (SD: 18.6) Ast: 78.4 (SD: 12.6)	PLCC: 24.5 Ast: 35.6	PLCC: p<0.001 Ast: p<0.001	PLCC: 1.20 Ast: 2.18

	Health-related quality of life	PLCC: 130 Ast: 171	PLCC: 75.5 (SD: 11.8) Ast: 81.2 (SD: 12.2)	PLCC: 77.2 (SD: 13.0) Ast: 82.8 (SD: 12.7)	PLCC: 1.7 Ast: 1.6	PLCC: p = 0.020 Ast: p = 0.034	PLCC: 0.137 Ast: 0.128
	Life satisfaction	PLCC: 127 Ast: 170	PLCC: 7.4 (SD: 1.9) Ast: 8.1 (SD: 1.6)	PLCC: 7.5 (SD: 1.7) Ast: 8.3 (SD: 1.7)	PLCC: 0.1 Ast: 0.2	PLCC: p = 0.432 Ast: p = 0.153	PLCC: 0.055 Ast: 0.121
Yuan et al	Quality of life (infants)	Int: 178 Con: 151	Int: 10.33 (SD: 5.5) Con: 10.11 (SD: 5.22)	Int: 4.23 (SD: 3.51) Con: 5.08 (SD: 4.25)	Int: -6.1 Con: -5.03	Int: p < 0.001 Con: p < 0.001	Int: 1.32 Con: 1.06
	Quality of life (children)	Int: 96 Con: 83	Int: 8.69 (SD: 5.92) Con: 8.19 (SD: 5.22)	Int: 4.71 (SD: 4.32) Con: 5.43 (SD: 4.36)	Int: -3.98 Con: -2.76	Int: p < 0.001 Con: p < 0.001	Int: 0.670 Con: 0.574

Int: Intervention, Con: Control, Mod: ModuS, CAE: Conventional Asthma Education, MyATE: My Asthma Therapeutic Education, IEAS: Individual Education by Asthma Specialist, PLCC: Population with Less Common Chronic Conditions, Ast: Population with Asthma

Appendix 5: Table 7: Between group results

Study	**Outcome measure**	**Mean post-program (Intervention)**	**Mean post-program (control)**	**Population size**	**P value**	**Effect size (g)**	**PEDro Score**
Gurhoper et al	N/A	N/A	N/A	N/A	N/A	N/A	6
Ernst et al	Knowledge	78.5 (SD: 12.6)	75.9 (SD: 13.3)	Mod: 166 CAE: 158	0.044	0.201	5
	Health-related quality of life	82.6 (SD: 13.4)	82.9 (SD: 12.3)	Mod: 182 CAE: 149	0.318	0.023	
	Satisfaction with life	8.0 (SD: 2.8)	7.9 (SD: 3.5)	Mod: 185 CAE: 144	0.712	0.032	
Dardouri et al	Quality of life	6.29 (SD: 0.78)	5.39 (SD: 1.10)	MyATE: 34 IEAS: 34	0.001	0.944	5
Menrath et al	Knowledge	75.3 (SD: 18.6)	78.4 (SD: 12.60.199)	PLCC: 125 Ast: 156	N/A	0.199	4

	Health-related quality of life	77.2 (SD: 13.0)	82.8 (SD: 12.7)	PLCC: 130 Ast: 171	0.479	0.436	
	Life satisfaction	7.5 (SD:1.7)	8.3 (SD: 1.7)	PLCC: 127 Ast: 170	0.554	0.471	
Yuan et al	Quality of life (infants)	4.23 (Sd: 3.51)	5.08 (SD: 4.25)	Int: 178 Con: 151	N/A	0.220	6
	Quality of life (children)	4.71 (SD: 4.32)	5.43 (SD: 4.36)	Int: 96 Con: 83	N/A	0.166	

Int: Intervention, Con: Control, Mod: ModuS, CAE: Conventional Asthma Education, MyATE: My Asthma Therapeutic Education, IEAS: Individual Education by Asthma Specialist, PLCC: Population with Less Common Chronic Conditions, Ast: Population with Asthma

Appendix 6: Figure 2: Van Tulder Best Evidence Synthesis (Levels of Evidence)

Van Tulder's best evidence synthesis involves four levels of evidence, each with increasing strength:

1. Strong evidence: Based on at least two high-quality randomized controlled trials that show consistent, statistically significant results.
2. Moderate evidence: Based on at least one high-quality randomized controlled trial, or multiple lower-quality studies that show consistent, statistically significant results.
3. Limited evidence: Based on one or more lower-quality studies that show consistent, statistically significant results.
4. Inconclusive evidence: Based on conflicting or insufficient evidence from multiple studies.