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PELICAN: Content Evaluation of Patient-Centered Care for Children With Asthma Based on an Online Tool

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SUMMARY.

Background: We assessed the content of an intervention which integrates individual goals in outpatient clinic asthma management (based on self management principles) of children 6–12 years of age. **Methods:** This is a content evaluation study and was part of a randomized controlled multicenter trial with 9 months follow-up in five Dutch outpatient asthma clinics among children with asthma aged 6–12 years. Information on children’s individual problems and their level of impairment (as indicated by the Pelican instrument), asthma management goals, and actions (as indicated by written action plans) was collected. Satisfaction of parents, children, and nurses were assessed with questionnaires and analyzed with descriptive statistics. **Results:** Most frequently identified problems by children (n=442) were “cough,” “cigarette smoke,” and “shortness of breath.” Eighty-two percent of items that were selected by children showed room for improvement. About 2–7 actions were formulated and children had an active role in more than 76% of the actions. “Using rescue medication prior to activities/triggers,” and “talk to others about your asthma” were most frequently recommended. Children thought the Pelican instrument was easy (95%) and fun (65%) and both parents and nurses were positive about the incorporation of the program in asthma management. Following barriers were found: (1) only 25% of goals was formulated according to SMART principles;

(2) traditional management aspects (such as medication use) are often treated instead of individual problems of children. Conclusion: Implementation of patient-centered care based on the Pelican instrument is recommended in specialized care, although more extensive training of nurses in PCC will improve the successful execution of the evaluated treatment. *Pediatr Pulmonol.* 2016;51:993–1003.

ABBREVIATIONS

ADHD Attention deficit and hyperactivity disorder

GP General practitioner

HRQL Health-related quality of life

PCC Patient-centered care

RCT Randomized controlled trial

SMART Specific measurable acceptable realistic and time-bound

WAP Written action plan

INTRODUCTION

Asthma is one of the most common chronic illnesses among children in Western countries.^{1,2} It is an inflammatory pulmonary disease with variable and recurrent symptoms such as wheezing and shortness of breath.³ Treatment consists primarily of avoiding triggers (e.g., exposure to allergens), improving physical condition, and controlling symptoms with medications. Since patients play an important role in managing asthma, taking their perception into account and stimulating self management is recommended.^{4,5} Although previous research has already shown favorable results of self management and educational interventions on reducing childhood asthma morbidity, there have been no previous studies—to the best of our knowledge—to integrate children's personal goals and solutions in self management for asthma.^{6–9} We have developed an asthma-specific health-related quality of life instrument (HRQL; Pelican instrument) that enables children to indicate asthma-related problems that bother them mostly in daily life.^{10–14} The selected problems are the starting point of a nurse-guided patient-centered care (PCC) program based on self management principles.

The nurse supports children and parents in specifying their needs, formulating treatment goals, and deciding on appropriate actions that are written down in an action plan.

We performed a randomized controlled study in pediatric outpatient clinics to assess whether nurse-guided PCC was effective in improving children's HRQL in 9 months. Results of this study indicate beneficial effects on asthma-specific HRQL in a relevant proportion of primary school aged children with asthma¹⁵ (full article not yet published at this point). Since PCC programs are complex interventions that are adjusted to individuals and often consist of several treatment phases, a detailed evaluation of the intervention is crucial to understand how and why a PCC program works or fails.¹⁶ Successful implementation depends on agreement and active engagement of children, parents, and health care professionals. In this paper we analyze the children's selection of asthma-specific problems using the Pelican instrument and the way these were integrated in written action plans. Furthermore,

we report observations regarding the supportiveness of children, parents, and nurses to participate in the PCC program.

MATERIALS AND METHODS

Design, Randomization, and Ethics Approval

We carried out a 9-month randomized controlled trial (RCT) in five hospitals to assess the effectiveness of integrating primary school-aged children's individual treatment goals in the outpatient management of pediatric asthma in the Netherlands. Both official caregivers (if applicable) gave written informed consent before any study procedure took place. We assigned children to patient-centered care (PCC in addition to usual care; intervention group) or usual care alone (UC; control group) in a 1:1 ratio using minimization software (Minim) that forced a balance between study arms for age (6–8 vs.

9–11 years old) and asthma control (Asthma Control Questionnaire 6 (ACQ6) score <1 vs. ≥ 1).^{17,18} Participating siblings were assigned to the same treatment arm based on the minimization code of the first recruited child.

Children, parents, and nurses were aware of treatment allocation. Subjects were followed for nine months with four scheduled visits. Ethics approval was obtained from the Medical Ethics Committee (file number 2009/292).

Study Sample

Children that were included in the analyses for the current paper participated in the previously described RCT and were allocated to the intervention group. Children had physician-diagnosed asthma, were 6–12 years of age, and used asthma medication (i.e., bronchodilators and/or inhaled corticosteroids) for at least 6 weeks during the previous year. Exclusion criteria were comorbid conditions that significantly influence HRQL (such as diabetes or congenital heart defects), not being able to attend a regular school class (as an indicator of normal intelligence), and insufficient skills in speaking, and/or reading the Dutch language. Other study subjects for this paper were the parents/caregivers of the participating children and the nurses that treated children in the intervention group.

Nurse-Led Patient-Centered Care

Starting point of the PCC as provided in the study was the child's outcome on the Pediatric Electronic quality of Life Instrument for Childhood Asthma in the Netherlands (Pelican). This is an online self-administered asthma-specific HRQL questionnaire for primary school-aged children.¹⁰ All parents are instructed to let the child complete the instrument by him/herself, unless the child requires help in order to do this. The child is asked to select a minimum of one and a maximum of three items from a pre-selected list of personal asthma-related problems (such as wheezing, medication use, not allowed to caress pets). This list is based on results of a focus group study on aspects considered essential according to Dutch primary school-aged children with asthma.^{10,18} Furthermore, the child can add one extra individual problem that is not present in the pre-selected list.

Figure 1 shows a screen shot of the individual selection part of the Pelican instrument. The selection of the child's asthma-related problems is forwarded to the nurse who sees children to provide PCC. Together with the child and parent(s), a nurse discussed which selected problem would be prioritized for treatment (Step 1).

Details around the chosen problem were discussed (Step 2) and a treatment goal was chosen through shared decision making. Goals were formulated according to SMART (specific, measurable, acceptable, realistic, and timebound) principles (Step 3).¹⁹ Next, possible solutions were discussed during a fun and quick brainstorm with all solutions on which mutual agreement was achieved and documented in a written action plan (Step 5). All solutions were formulated as concrete as possible (who, what, when) and the nurse performed a feasibility and motivation check with parents and children. Although only one problem per visit was intended to be discussed, the WAP allowed elaboration on two problems. During the next visit, the results of the written action plan were evaluated (Step 6) and if the treatment goal had not been achieved, the six-step intervention was repeated.

During a 2-hr meeting before the start of the study, nurses were trained in interpretation of the Pelican outcome, the six-step PCC program, motivational communication, and selfmanagement support. Elements of the six-step program that were highlighted were how to coach children and parents in formulating a treatment goal according to SMART principles and to stimulate them during a creative brainstorm. Nurses were also given an instruction with examples of solutions for different problems in the preselected list of the Pelican instrument.

In addition, five scheduled personal consultation moments and continuous support for specific questions that nurses might have, were provided on request at all times by one of the investigators (SB).

[FIGURE 1]

Data Collection and Analyses

Demographic data of the participants were collected at the start of the study by means of a proxy questionnaire.

PCC intervention content was recorded in the written action plans (WAPs). General satisfaction with PCC was investigated by questionnaire among all stakeholders 1 month after a child had finished the study.

Goals and actions as documented in the WAPs were labeled categorized by two investigators independently (SB, RC). In case of a difference in agreement between the two investigators, a third reviewer (LB) also labeled and categorized the data. Categorized data that showed agreement between two and three reviewers was used, otherwise consensus was reached through discussion.

After the study, information was gathered on satisfaction with PCC (including the Pelican instrument) by a questionnaire from children, parents, and nurses. All data were analyzed by means of descriptive statistics.

RESULTS

Study Population in Primary and Specialized Health Care

Three hundred and twenty-four children from five hospitals were invited between August 2011 and March 2013. One hundred and one children were randomized and 97 started in the study (46 in the PCC group and 51 in the usual care group). Finally, 42 children in the intervention group were included in the current analyses (four children had too many missing values).

Figure 2 shows a flow chart of participation recruitment and Table 1 shows baseline demographic and clinical characteristics of these children.

Content of the Patient-Centered Care Program

Children's Problem Experiences (Pelican Instrument)

In total, the children selected 352 asthma-related problems in the Pelican instrument with a median of three problems per child per visit. The most frequently selected asthma-related problems during the first three visits were “cough,” “cigarette smoke,” and “shortness of breath” (Table 2). Children used the opportunity to add an individual problem (34 problems, 9.7% of all selected problems) besides those on the pre-selected list. In 18 of these cases, the child used this option to add a fourth item from the preselected list, leaving 16 distinct individual problems (4.6%), such as “hay fever.” Although, the Pelican instrument is self-administered, nurses mentioned during personal consultation that some parents thought their child was unable to oversee his/her asthma-related problems and to provide reliable answers without parental help.

Content of the Written Action Plans

Nurses indicated on the written action plan which problems were discussed. Treatment goals were formulated, and agreed solutions written down per problem. A total 101 WAPs were completed for the repeated visits of the 42 participating children, with a total of 113 problems being addressed during these visits. The most frequently chosen problems in WAPs were “medication use,” “running,” and “cigarette smoke” (Table 2). Reasons (according to nurse) to not discuss any problems were: the child did not complete the Pelican instrument (8), the problems selected by the child were not severe enough to treat (14), the child did not answer reliably on Pelican instrument (4), a lack of time (2), lack of motivation of the child (2), other problems were more important (2), problems unlikely to be susceptible to change (1), parent(s) and children lacked capacity to manage problems (1) (overlap in reasons was possible).

On every action plan a treatment goal was formulated per problem, however formulating according to SMART principles only occurred in 25% of the WAPs. In most cases, goals were not specific or measurable. Two to seven actions per problem were defined per treatment goal.

“Using rescue medication prior to activities/triggers,” and “talk to others about your asthma” were the most frequently defined actions (Table 3). Actions that showed most improvement on problem scores (i.e., percentage of children showing improvement $\geq 50\%$ and mean change ≥ 0.70) were “improve physical condition,” “improve medication inhalation technique,” “optimize availability of inhaler,” and “monitor asthma symptoms.” In 224 out of 294 actions (76.2%) an active contribution of the child was required, in 99 actions (33.7%) of the parent(s), in 31 actions (10.5%) of the nurse, and in 14 actions (4.8%) action of another/unspecified party (overlap in active contribution was possible). A flow chart of PCC completion is shown in Figure 2.

Satisfaction With the Patient-Centered Care Program

Table 4 shows results on satisfaction with PCC after each visit by a subset of parents ($n=35$; $n=16$) and nurses ($n=45$). General satisfaction was also investigated 1 month after the study in the children and parents. Eleven parents did not complete the final survey.

During personal consultations with the investigators, nurses mentioned some doubts and barriers. Nurses thought that children were often unable to distinguish between “current” and “recent” problems and often relied on old memories, especially when asthma-related problems, such as exacerbations, had had a substantial emotional impact. Furthermore, two nurses felt that there were hardly any acceptable solutions when children were not allowed to keep a pet. Also, the nurses concluded that implementing PCC was more difficult for young children (6–8 years) and children with comorbidity, especially Attention Deficit Hyperactivity Disorder (ADHD).

[FIGURE 2]

DISCUSSION

The aim of this study was to describe the content of the PCC intervention and the supportiveness of respective stakeholders to integrate PCC in pediatric asthma management. We used information from children, parents, and nurses that were allocated to the PCC treatment arms of a randomized controlled trial in five Dutch outpatient clinics.

A total of 42 children with asthma were treated with nurse-led patient-centered care besides usual care. Our findings show that children selected a total of 352 asthma-related problems by using the Pelican instrument. The most detrimental treatment goals according to children were focused on problems such as “coughing,” “cigarette smoke,” and “shortness of breath.” The problems that children selected in the Pelican instrument showed enough room for improvement. Children evaluated the Pelican instrument as easy to complete and fun to do.

However, nurses mentioned that some parents thought their child was unable to oversee his/her asthma-related problems and to provide reliable answers without parental help. Although we do not have current data to support this, a previous validation study suggests limited usability of the Pelican instrument in very young children and children of non-Western ethnicity.¹⁰

[TABLE 1]

During consultation, a total of 113 problems as experienced by the children were discussed and put into 101 written action plans. Children, parents, and nurses formulated two to seven actions to attain treatment goals and children had an active role in most of the actions. “Using rescue medication prior to activities/ triggers,” and “talk to others about your asthma” were most frequently recommended. Both parents and nurses were positive about the incorporation of the program in asthma management. They felt that treatment was improved and that the WAP was a (very) useful instrument. Three in four parents were willing or not reluctant to continue with PCC after the end of the study, if this was offered. The following barriers were found: (1) only one in four treatment goals that were mentioned on action plans was formulated according to SMART principles; (2) the nurses often prioritized traditional management aspects (such as medication use) instead of the individual problems as indicated by the children.

These mentioned barriers show a mismatch between the intended aim of PCC to integrate personal goals of children in asthma treatment and the final implementation

of these goals. This mismatch occurred despite patient-centered training of the nurses at the start of the study.

This observation might be explained by the “habit” of health care providers to direct communication and transfer their own treatment goals instead of facilitating treatment responsibility in patients and parents or informal caregivers.²⁰ To the best of our knowledge, this is the first time that individual child-reported outcome measures are integrated in asthma management, enabling personalized health-care for this patient population. Only two earlier studies investigated an interactive program that used patients’ outcomes on asthma symptoms, quality of life, and/or medication use to direct asthma disease management.

^{21,22} These studies reported improvement on self management skills, asthma symptoms, asthma control, lung function, and other outcomes. However, in contrast to our program, the feedback to the children consisted of predefined responses based on the child’s entries in these programs and did not result in a personalized action plan.

[TABLE 2]

Strengths and Limitations

The current study describes the content of care of PCC for childhood asthma, as an important addition to the results of an effectiveness study that was performed in specialized care.¹⁷ A content evaluation is an important aspect of complex interventions and provides insight into the “black box” why an intervention works or fails.

This is the first time that the integration of a Patient-reported Outcome Measure (PROM, as measured by the Pelican instrument) in a PCC treatment leading to a personalized action plan is evaluated in such a young group of asthma patients. Usually, the use of PROMs leads to standardized action plans. We believe that the process of shared decision making in patient-centered care is very important in future asthma management to improve therapy adherence. Poor adherence to therapy and inadequate treatment are two important reasons why asthma is uncontrolled.^{23,24} Poor adherence has been associated with discrepancies between the perceived relevance of treatment goals between patients and their health care providers. Therefore, taking the child’s perception into account in the management of its asthma could result in achieving treatment goals of both patients and providers.

The data we collected was mainly quantitative.

Collecting additional qualitative information on the process, for example by interviews, would have enriched our evaluation but was considered an extra burden for participants as study participation was already rather demanding. Despite quite a bit of missing data, relevant information on barriers and facilitators was obtained during this study.

Due to a small number of treated children with PCC (n=42), it was not possible to perform subgroup analyses to see what “type” of patient benefits most of PCC treatment. It would, for instance, have been interesting to investigate differences between children with/without asthma control, with optimal/suboptimal quality of life, and with/without psychosocial problems.

It could be discussed whether a follow-up period of 9 months is enough to achieve lasting behavior change and improvement in quality of life in the children and

parents that participated in this study. Therefore, it would have been interesting to investigate all elements of the behavior change model (e.g., attitude, knowledge, self-efficacy, and health behavior) during a longer period of time.

[TABLE 3]

Recommendations for Future Research

In addition to this content evaluation, it is required to perform a process evaluation as well to gain full comprehension on how and why a complex intervention works or fails. In addition, implementation of the evaluated Patient-Centered Care program was executed in the context of a randomized controlled trial.

Ideally, further investigation in real life conditions is performed. Self management requires enough capacity and skills of patients to gain insight into their chronic illness and treatment decisions. Some parents and nurses suggested that young aged children (6–8 years of age) were not always capable of providing reliable answers on the Pelican instrument or to actively participate in conversation about asthma management. This also applied to children with ADHD. Further research on specific subgroups is recommended. Furthermore, it would be interesting to investigate a program that is individualized on visit frequency and severity of asthma problems as well. Assessing the cost-effectiveness of PCC will be the topic of further research by our research group.

[TABLE 4]

Advice for Clinical Implementation

If and when PCC is being implemented in outpatient clinics in the Netherlands, we believe nurse-involvement is inevitable since personalized disease management takes considerable time and effort. According to a recent Cochrane review and another study in the Netherlands, nurse-led care for patients with asthma is equally effective compared to physician-led care for the outcomes assessed.^{25–27} Whether nurse-led PCC treatment according to the evaluated six-step program is feasible for countries with different health care systems is unclear. Need for PCC, feasibility and effectiveness should be investigated for every health care setting separately, because careless extrapolation could lead to high costs without the desired health achievements. Important to mention is the fact that PCC was offered in addition to usual care and not as a replacement of usual care. This would make the intervention easier to implement in other health care systems as well.

This content evaluation shows that a couple of aspects of PCC treatment need improvement; nurses require more extensive and continuous training to keep paying attention to children's individual asthma-related problems according principles of shared decision making and motivational interviewing. In addition, they require more training in formulating goals according SMART principles.

CONCLUSION

We conclude that PCC for children with asthma seems to be acceptable in specialized care for all stakeholders, and can be recommended for use in this setting after a cost-effectiveness study. However, nurses required enduring training on

patient-centeredness since there still seems to be room for improvement with regard to goal setting.

AUTHORS' CONTRIBUTIONS

S. van Bragt, L. van den Bemt, and T. Schermer have developed the protocol. L. van den Bemt and T. Schermer applied for funding. P. Merkus contributed to the practical and clinical applicability of the trial design in the preface of the study. S. van Bragt, L. van den Bemt, and R. Cretier reviewed the written action plans. R. Cretier managed the logistics and data collection for this study. All authors read, contributed, and approved the final manuscript.

The lead author, S. van Bragt, affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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TABLES AND FIGURES

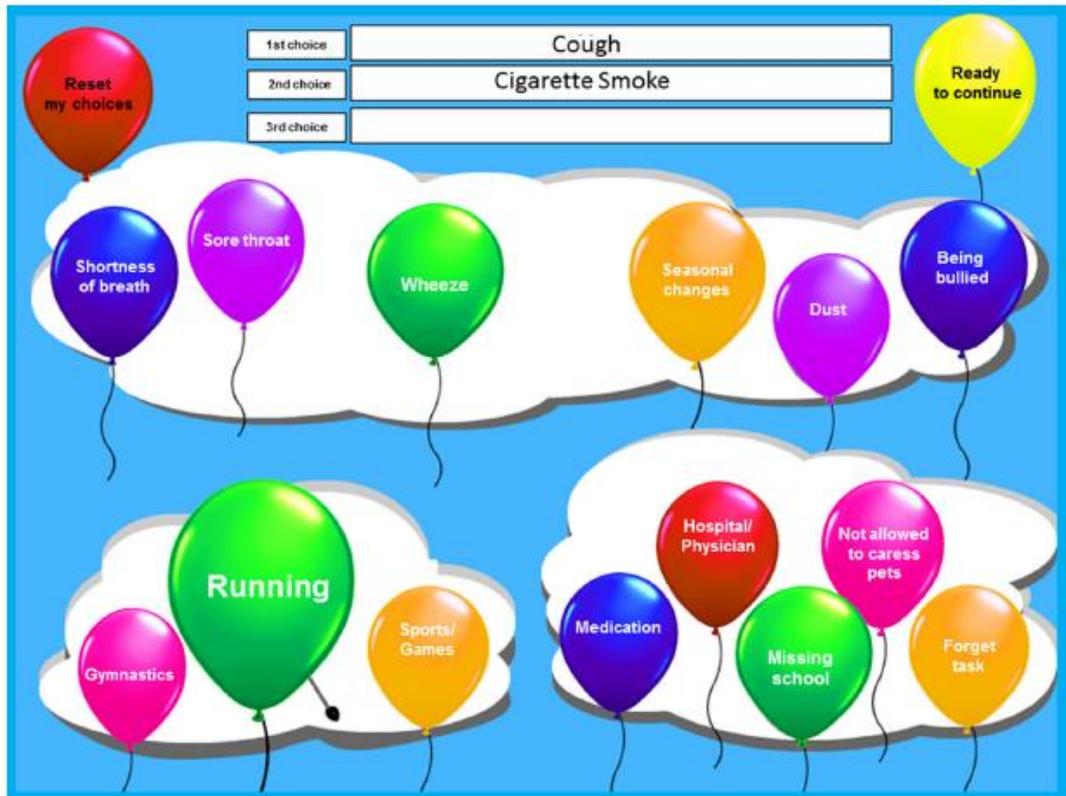


Fig. 1. The individual part of the Pelican instrument.

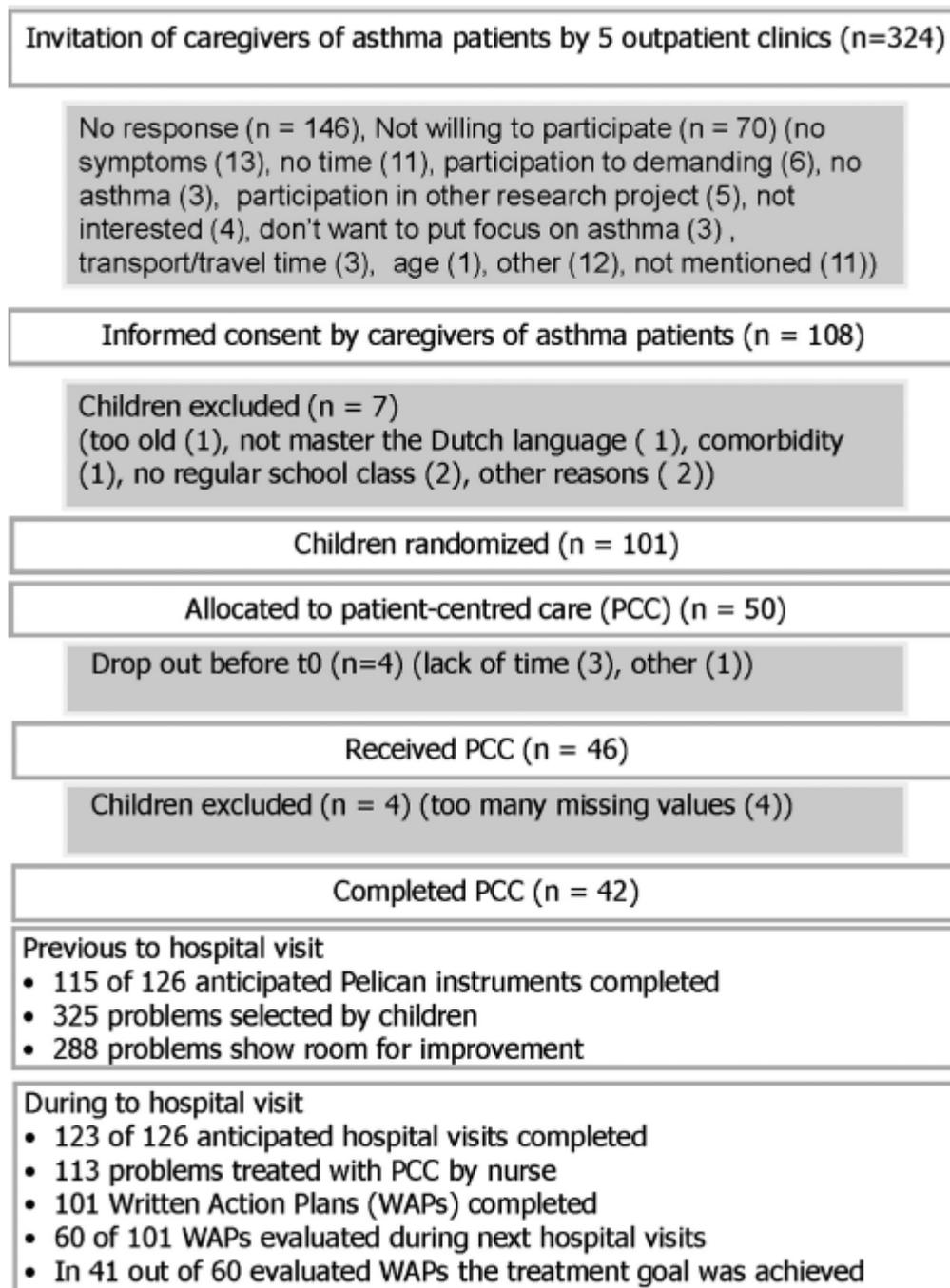


Fig. 2. Flow chart of participant recruitment and patient-centered care completion.

TABLE 1—Demographic and Clinical Characteristics of Subjects Receiving Individualized Self-Management Treatment in Specialized and Primary Care

	n	Specialized care (n=42) median (IQR)
Gender (n male, %)	42	25 (59.5)
Age (mean, SD)	42	8.7 (1.5)
Ethnicity (n, %)	42	
Dutch		33 (78.6)
Western immigrant		2 (4.8)
Non-western immigrant		7 (16.6)
Education level of parents (n,%)	42	
Low		6 (14.3)
Mid		12 (28.6)
High		24 (57.1)
Asthma control (C-ACT)	39	18.8 (17.2–20.3)
Well controlled >22 (n, %)		11 (28.2)
Uncontrolled ≤22 (n, %)		28 (71.8)
Lung function	41	
FEV1% pred ^a (L) (mean, SD)		1.75 (0.4)
Reversibility (n,%)		11 (26.8)
Medication use (n, %)	41	
Inhaled corticosteroids		34 (82.9)
Short-acting beta-adrenoceptor agonist		27 (65.9)
Long-acting beta-adrenoceptor agonist		9 (22.0)
Health-related quality of life (PAQLQ-s)	42	5.64 (4.90–6.24)
Activities		5.55 (4.75–6.00)
Emotions		6.87 (6.34–7.00)
Symptoms		5.20 (4.38–6.30)
Health-related quality of life (Pelican) (mean, SD)	42	2.52 (0.76)
Activities		1.67 (1.00–2.31)
Triggers		2.80 (2.00–3.20)
Symptoms		2.80 (2.20–3.85)
Asthma management		2.63 (1.94–3.75)
Social/emotional		1.75 (1.00–2.31)
Psychosocial problems (SDQ) ^b (mean, SD)	40	10.30 (5.82)
Normal (n, %)		28 (66.7)
Minor (n, %)		6 (14.3)
Major (n, %)		8 (19.1)

ACQ, asthma control questionnaire; C-ACT, child-asthma control test; IQR, inter quartile range; PACQLQ, paediatric asthma caregiver quality of life questionnaire; PAQLQ-s, paediatric asthma quality of life questionnaire with standardized activities; PELICAN, pediatric electronic quality of life instrument for children with asthma in the Netherlands; SD, standard deviation; SDQ, strengths and difficulties questionnaire.

^aReference values used of Global Lung Initiative 2012 (GLI).

^bSDQ question 13 was missing among 90 of 92 subjects due to organizational problems and was imputed with individual mean of scale.

TABLE 2—Overview of Selected Asthma-Related Problems in the Pelican Instrument That Were Completed (n = 115) by 42 Children and the Integration of These Problems in Patient-Centered Care During Three Visits in Outpatient Clinics in the Netherlands

Asthma-related problem/item (Pelican)	Number of times selected by children	Number of times that this problem shows room for improvement ^a		Number of times this selected problem was used during PCC		Actual number of times this problem was discussed during PCC ^e
	N	n ₁	% (n ₁ /N)	n ₂	% (n ₂ /n ₁)	n
Cough	48	38	79.2	8	21.1	10
Cigarette smoke	36	27	75.0	9	30.9	10
Shortness of breath	33	24	72.7	6	25.0	8
Not allowed to caress pet	30	30	100.0	8	26.7	9
Seasonal changes	29	24	82.8	3	12.5	3
Sore throat	28	22	78.6	7	31.8	8
Dust	25	17	68.0	3	17.7	3
Medication	23	16	69.6	12	75.0	19
Running	22	21	95.5	7	33.3	12
Wheeze	18	15	83.3	7	46.7	7
Individual problem ^a	16	16	100.0	5	31.3	5
Missing school	12	11	91.7	2	18.2	2
Sports/games	10	9	90.0	3	33.3	6
Hospital/physician	10	7	70.0	0	00.0	0
Being bullied	6	5	83.3	3	60.0	5
Forget task	5	5	100.0	1	20.0	1
Gymnastics	1	1	100.0	0	00.0	0
Other problem				29 ^b		5 ^c
Total	352	288	81.8			113

^aIndividual asthma-related problems other than the selection of a fourth problem from the preselected list by the child in the individual question: limitations due to being ill or having a cold (n = 3), often easily tired (n = 4), not being able to hurry and having to act calm (n = 1), cycle (n = 1), allergies or hay fever (n = 4), forget medication (n = 1), stomach hurts (n = 1), smoking/gymnastics/playing outside (n = 1).

^bOther problem: individual problem mentioned by child that was not on the predefined list. This was a problem a child could fill out as an extra option.

^cOther problem: problem selected for treatment was not based on child response on the Pelican instrument. This was a complete new problem that often came up during consultation with the nurse.

^dScore ≥ 3 on Pelican instrument.¹⁰

^eActual number of times this problem was discussed during PCC irrespective of whether problem was selected by the child or not.

TABLE 3— Actions in Written Action Plans (Actions n = 290; WAP n = 101) During Three Visits Leading to Change in Asthma-Related Problems (Improved/Unchanged/Deteriorated/Missing^a)

Action	No. of times action was used		Problem score change known	Problem score change	Problem improved		Problem unchanged		Problem deteriorated	
	n	%	n	Mean (SD)	n	%	n	%	n	%
Use asthma medication before activity or trigger	37	12.6	31	0.10 (1.35)	10	32.3	14	45.2	7	22.6
Talk to others concerning asthma-related problems	31	10.5	26	0.00 (1.90)	10	38.5	9	34.6	7	26.9
Adjust dose/frequency of asthma medication	17	5.8	13	0.00 (1.00)	3	23.1	7	53.8	3	23.1
Rinse mouth/drinking water	17	5.8	15	0.13 (1.13)	7	46.7	3	20.0	5	33.3
Receive information/education on asthma	14	4.8	11	0.45 (1.37)	4	36.4	5	45.5	2	18.2
Warming up	13	4.4	11	-0.36 (1.36)	3	27.3	5	45.5	3	27.3
Improve asthma medication inhalation technique	11	3.7	10	0.80 (0.92)	7	70.0	2	20.0	1	10.0
House sanitation/ventilation	11	3.7	7	0.29 (0.76)	3	27.3	3	27.3	1	9.1
Optimize availability/repository of inhaler	9	3.1	9	0.78 (1.64)	5	55.6	3	33.3	1	11.1
Improve physical condition	8	2.7	6	0.83 (1.17)	3	50.0	3	50.0	0	00.0
Avoid trigger/walk away from trigger (e.g., cigarette smoke)	8	2.7	7	0.57 (0.79)	3	42.9	4	57.1	0	00.0
Pet animals somewhere else (when not allowed at home)	8	2.7	8	0.25 (0.46)	2	25.0	6	75.0	0	00.0
Adjust timing of asthma medication intake	7	2.4	7	0.57 (0.79)	3	42.9	4	57.1	0	00.0
Educate class mates or others	7	2.4	7	0.71 (2.76)	3	42.9	3	42.9	1	14.2
Reminder system for asthma medication use	7	2.4	6	0.33 (1.63)	3	50.0	1	16.7	2	33.3
Parent/other does not smoke in presence of child	7	2.4	6	0.67 (0.82)	3	50.0	3	50.0	0	00.0
Gradual temperature transition	6	2.0	5	0.00 (1.23)	2	40.0	2	40.0	1	20.0
Reward system for child in agreement with caregivers	6	2.0	6	-0.17 (2.14)	3	40.0	1	16.7	2	33.3
Use throat emollients	6	2.0	4	0.50 (1.29)	2	50.0	1	25.0	1	25.0
Acting calm/taking rest (in general)	4	1.4	2	0.50 (0.71)	1	50.0	1	50.0	0	00.0
Change medication agent	4	1.4	4	0.75 (1.50)	1	25.0	3	75.0	0	00.0
Monitor asthma symptoms	4	1.4	4	0.75 (1.26)	3	75.0	0	00.0	1	25.0
Making doctor's appointment on time/frequently	3	1.0	2	1.50 (3.54)	1	50.0	0	00.0	1	50.0
Referral to specialist	3	1.0	1	1.00 (/)	1	100.0	0	00.0	0	00.0
Wash hands after contact with animal	3	1.0	3	0.33 (0.58)	1	33.3	2	66.7	0	00.0
Regulate breathing	2	0.7	2	0.00 (0.00)	0	00.0	2	100.0	0	00.0
Other action	41	14.0	36	0.58 (1.23)	15	41.7	18	50.0	3	8.3
Total actions	294	100.0	249		102	41.0	105	42.1	42	16.9

The formulated action can apply to several problems. The mean change on item score is based on all selected problems for which this action was formulated in the written action plan.

/ means not applicable (n.a.).

^aBetter item score on Pelican instrument was a change of ≤ -1 , equal was the same score and worse was ≥ 1 . Missing data were caused by incompleteness of the Pelican instrument by the child before one of the four scheduled visits or individual problems treated.

TABLE 4—Satisfaction With PCC Management of Asthma in Specialized Care in the Netherland by Children (n = 40), One of Their Parents (n = 31) and Nurses (n = 5)

Satisfaction items	Criterion	Unit	N	n (%)	
Do children with asthma think it is fun to complete the Pelican instrument? (Note: n=2 missing)	(Very) fun	Children	40	26 (65.0)	
	Neutral			6 (15.0)	
	Not fun (at all)			8 (20.0)	
Do children think it is difficult/easy to complete the Pelican instrument?	Not difficult (at all)	Children	40	38 (95.0)	
	Neutral			1 (2.5)	
	(Very) difficult			1 (2.5)	
Remarked by children that instrument is somewhat childish		Children	40	5 (12.5)	
	Is ISM support better adjusted to the needs of your child than usual care, according parents?	Generally improved	Parents	31	10 (32.3)
		More or less the same			16 (51.6)
		Generally deteriorated			1 (3.2)
Otherwise		4 (12.9)			
Is the WAP useful according parents?	(Very) useful	Parents	31	19 (61.3)	
	Not useful/not useless			6 (19.4)	
	(Very) useless			3 (9.7)	
	Otherwise			3 (9.7)	
Parents opinion on appropriateness of management strategies to solve problem according to a subset of parents (n=16) with in-depth process information.	(Very) appropriate	3 evaluations (8 missing) in a subset of parents	38	32 (84.3)	
	Neutral			4 (10.5)	
	(Very) inappropriate			2 (5.2)	
Parents opinion on the helpfulness of management strategies to solve problem according to a subset of parents (n=16) with in-depth process information.	(Very) helpful	3 evaluations (8 missing) in a subset of parents	38	20 (64.5)	
	Neutral			5 (16.1)	
	Not helpful			3 (9.7)	
	Otherwise			3 (9.7)	
Would parents like to continue with ISM support after the study?	Absolutely/Probably I don't mind	Parents	31	16 (51.6)	
	Absolutely/Probably not			7 (22.6)	
	Otherwise			6 (19.4)	
				2 (6.5)	
Is the child's outcome of the Pelican instrument comprehensible according to the nurses?	Most of the times	Nurses	5	3 (60.0)	
	Sometimes			2 (40.0)	
Is the outcome of the Pelican instrument susceptible to change according to the nurses?	Most of the times	Nurses	5	2 (40.0)	
	Sometimes			3 (60.0)	
Did nurses think the PCC consult was useful for children?	(Very) useful	Evaluations of visits (11 missing)	112	97 (86.6)	
	Not useful/not useless			12 (10.7)	
	(Very) useless			3 (2.7)	
Would nurses advise ISM support to their colleges?	Yes	Nurses	5	5 (100)	
Mean grade of Pelican instrument and ISM support, given by nurses (between 0-10)		Points	7.4 (0.89)	6.7;8.8	