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Nurse-delivered outpatient asthma education for children and caregivers: a pilot study to promote shared asthma management

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ABSTRACT

Objectives: To assess the feasibility of nurse-delivered asthma education for caregiver/child dyads in a busy clinic setting, and measure the preliminary effectiveness of the intervention.

Methods: We conducted a pilot study of nurse-delivered asthma education in a busy outpatient clinic. We enrolled a convenience sample of children (7–16 years) with uncontrolled persistent asthma who had a prescription for an inhaled controller medication and public health insurance. After provider visits, nurses taught dyads using picture-based materials, teach-back methods, and colored labels applied to asthma medications. The intervention was repeated at 1-month follow-up. We assessed feasibility by reviewing nurse documentation in the electronic medical record, detailing whether each component was implemented and the time required for education at each visit. We measured preliminary effectiveness by surveying children and caregivers separately before each clinic visit about asthma management responsibility, self-efficacy, caregiver quality of life, and symptoms; caregivers also completed a final telephone survey 2 months after the follow-up visit. We examined pre-post differences in continuous outcomes within-subjects using Wilcoxon signed rank tests.

Results: We enrolled 22 child/caregiver dyads. Nursing documentation indicated a high rate of component delivery at each visit; the initial and 1-month visits required 25 and 15 min, respectively. We observed significant increases in child responsibility, child/caregiver self-efficacy, caregiver quality of life, and child symptoms at each follow-up.

Conclusion: This intervention of patient-centered asthma education can be delivered by nurses to caregiver/child dyads with high fidelity in a busy pediatric practice. Preliminary data indicate potential benefit for both children and caregivers.

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Introduction

Seven million children under the age of 18 years are diagnosed with asthma in the United States (1). Children who are poor, live in urban areas, or come from minority racial/ethnic backgrounds continue to be disproportionately impacted through higher prevalence and increased morbidity (2–6), including higher rates of asthma-related hospitalization and emergency room use, missed school, and a decreased quality of life. These disparities persist despite evidence that patient education (7–9) and self-management support (10) can improve asthma outcomes. Indeed, the educational partnership between patients and providers has been a cornerstone of asthma management since national guidelines were first published in 1991 (11).

Although most primary care providers agree with this emphasis on preventive education (12), and are well-positioned to promote effective home management

that might reduce morbidity, clinic-based asthma education is not provided for many high-risk children with uncontrolled persistent asthma (13). As a result, these children miss out on key opportunities to improve home care practices. Decision-support tools and provider prompts increase rates of provider-led education (14, 15), yet time pressures on outpatient providers remain. In fact, competing demands on time are often cited as a reason why providers do not deliver guideline-based care, including patient education (16).

When clinic discussions about home management do occur, pediatric patients are often excluded by providers or caregivers (17–19). Most children and adolescents want to participate (20–22), however, and are more adherent with controller therapy when involved (23). Increasing child knowledge about asthma also improves patient self-efficacy and self-management skills (24). Education to help families manage chronic

pediatric diseases like asthma may only be effective when children participate (10); asthma education directed solely at caregivers will not benefit children who use medications independently or who share in asthma management responsibilities.

In reality, many children start to use asthma medications independently around ages 5–6 years (25, 26), and develop primary responsibility for medication use by early adolescence (26). Adolescent responsibility for using these medications is not associated with teen medication knowledge, however, such as the abilities to identify medications or describe indications for use (27). It is unsurprising that adherence to controller therapy is lowest in this age group (28, 29), as patients cannot be expected to follow a care plan that they do not understand and have not been counseled on. Nevertheless, caregivers may withdraw supervision from children they consider to be responsible for self-management, contributing to poor adherence and increased morbidity (30, 31). Children need to be engaged with patient-centered asthma education before they assume responsibility for their own care, and caregivers counseled about the importance of ongoing supervision as the child acquires self-management skills.

To our knowledge, few clinic-based educational interventions focus on developing self-management skills within caregiver/child dyads in the setting of persistent asthma. Previous interventions that do target dyads reported improved asthma outcomes, but did not promote co-management throughout the transition period (32), or engage children before the onset of responsibility (33). Our plan to educate caregivers and children as a dyad rather than as individuals aims to foster a sense of shared understanding, self-efficacy, and clarified responsibility for successful self-management. The goal of this pilot study was to assess the feasibility of implementing a nurse-delivered educational intervention designed to engage both caregiver and child in a clinic setting. We additionally sought to assess the preliminary effectiveness of the intervention on child and caregiver self-efficacy, responsibility for home management, child asthma symptoms, and caregiver quality of life.

Methods

Participants

We enrolled a convenience sample of children and caregivers attending a scheduled appointment for asthma or well-child care at an academic general pediatrics clinic in Rochester, New York. Patients between the ages of 7 and 16 years were eligible if they had a diagnosis of asthma and a prescription for an inhaled

controller medication documented in the electronic medical record (EMR); were covered by public health insurance (i.e. Medicaid or Medicaid managed care); and had caregiver-reported symptoms over the previous month consistent with uncontrolled asthma, as defined by National Asthma Education and Prevention Program (NAEPP) guidelines (34). Child/caregiver dyads were excluded if either member could not speak or understand English; if they had no access to a working phone (landline or mobile); if the child had another significant medical condition that could interfere with asthma assessment, including cystic fibrosis or congenital heart disease; or if the child had a diagnosed neurodevelopmental condition (e.g. autism spectrum disorder) that could influence the transition of responsibility for asthma management from caregiver to child.

We identified potential subjects through a weekly review of provider schedules in the EMR, and called caregivers to screen for eligibility (i.e. level of asthma control) within 24–48 h of a scheduled appointment. We met with caregiver/child dyads prior to the appointment to obtain written consent from caregivers, signed assent from teenagers (13–16 years old), and verbal assent from children ≤ 12 years old. If more than one child in a family met eligibility criteria, only one was enrolled into the study. We compensated caregivers for their time by providing a \$25 gift card after the initial, 1 month, and final assessments were completed. The University of Rochester Institutional Review Board approved of this study.

Intervention

We developed and piloted an intervention to provide consistent, patient-centered asthma education to children and caregivers in a general pediatrics clinic. All elements of asthma care that are identified in this section (both provider and nursing tasks) are considered to be part of the intervention. We notified providers when patients on their schedule were enrolled. During the clinic visit, providers were asked to: (a) determine whether changes to the child's treatment plan were indicated; (b) complete a written asthma action plan on paper; and (c) electronically transmit asthma prescriptions to the on-site outpatient pharmacy. All providers received verbal and written information about the intervention, and printed reminders were distributed at the point of care to ensure the completion of provider-specific tasks. The pharmacy agreed to expedite the filling of asthma prescriptions that they received for pilot subjects, and deliver medications to

clinic using an institutional pneumatic tube system. As all subjects had public health insurance, no medication copayments were required.

A pediatric registered nurse who had received training in intervention components and implementation delivered the education after the provider visit concluded. First, they reviewed “Let’s Take Control of Asthma!” with caregivers and patients. This picture-based tool, developed by the American Lung Association/Asthma Coalitions of Queens and Long Island, uses colorful pictures to introduce essential asthma management concepts (available on request). An associated script ensured standardization of teaching on asthma symptoms, triggers, controller and rescue medications, and how to use an asthma action plan. The nurse then reviewed the updated action plan that was developed during the provider visit. After prescriptions were delivered to clinic, the nurse provided colored stickers to distinguish controller from rescue medications following the action plan color scheme (green for controller medications, red for rescue medications). Patients applied the stickers to their medications under nurse supervision.

Next, the nurse demonstrated correct technique for using metered dose inhalers (MDI) with a spacer device, which was provided to each patient. Teach-back was used to determine whether both caregivers and children were able to: (a) state when each medication was supposed to be used; and (b) demonstrate correct MDI/spacer technique. If the patient did not have medications filled at the in-house pharmacy and delivered to the clinic, practice inhaler devices without medication were used for demonstration purposes. Finally, the nurse briefly discussed shared responsibility for asthma management within the family intended to reinforce the cooperative participation of both dyad members. Each caregiver received a folder with written information about community asthma resources, smoking cessation resources, the updated action plan, and picture-based instructions on correct MDI/spacer technique developed by the American Lung Association/Asthma Coalition of Erie County (available on request).

Each dyad was asked to return in 1 month for an asthma reassessment and follow-up teaching. Education at the follow-up was similar to baseline, with a couple of differences worth noting: “Let’s Take Control of Asthma!” was truncated to specifically reinforce lessons about symptoms and medications, and asthma medications were only refilled and re-labeled with colored stickers if caregivers indicated a need for refills.

Outcome assessment: feasibility

Our feasibility assessment focused on implementation and the practicality of delivering this intervention in a busy clinical setting (35). First, we wanted to determine whether the multifaceted intervention (both provider and nurse components) could be successfully enacted as planned under controlled circumstances within our busy clinical setting. We assessed implementation by reviewing process data captured in the EMR to quantify the delivery rate for different intervention components. Specifically, we monitored medication prescriptions sent from providers to the on-site pharmacy, and reviewed notes written by nurses after educational sessions. The existing EMR template for nursing notes about patient education was modified for this study to include information on whether program components were completed (Y/N). We assessed practicality by (a) monitoring nurse availability to provide teaching, and (b) asking nurses to document how much time they spent with caregiver/child dyads on planned educational activities. Our pediatric nurses are able to bill for time spent on asthma teaching (15 or 30 min); we wanted to know whether these existing parameters would accommodate the new intervention.

Outcome assessment: preliminary effectiveness

The PI or research assistant completed structured survey assessments with both caregivers and children (separately) within a private space in the clinic prior to the initial and 1 month appointments. A final follow-up assessment of caregivers was completed by telephone 2 months after the follow-up clinic visit (approximately 3 months after the initial visit). We asked caregivers to report demographic information (i.e. personal and child health history, smoke exposure, and family information) at baseline.

During each of the 3 planned assessments (i.e. baseline, 1 month, and final follow-up), caregivers described home asthma management responsibility using a nine-item scale. This survey, adapted from similar tools examining dyadic management of chronic childhood disease (36, 37), describes the locus of responsibility for nine asthma management tasks including controller medication use, getting prescription refills, and avoiding triggers. For each task, we asked respondents to state whether (a) the caregiver is primarily responsible (1 point), (b) the caregiver and child share responsibility (2 points), or (c) the child is primarily responsible (3 points). The combined score ranges from 9 points indicating full caregiver

responsibility for asthma management, to 27 points indicating full child responsibility.

We measured self-efficacy using the Parent Asthma Medication Self-Efficacy scale, a 13-question survey about perceived ability to use asthma medications (38). Caregivers selected responses on a 5 point Likert scale ranging from “Not at all sure” (1 point) to “Completely sure” (5 points). This self-efficacy score was generated by averaging the numeric responses across all items; a higher score indicates greater caregiver self-efficacy (range 1–5). We assessed caregiver asthma-related quality of life at baseline and final follow-up using Juniper’s 13-item Pediatric Asthma Caregiver Quality of Life Questionnaire (PACQLQ) (39), in which caregivers report their level of concern and disruptions to normal life due to childhood asthma on a 7 point scale; a higher mean score indicates a better asthma-related quality of life (range 1–7). Finally, caregivers reported child asthma symptoms over the previous 14 days using questions adapted from NAEPP guidelines (34), including the number of 24-h periods during which their child experienced daytime or nighttime symptoms, required rescue medication for acute symptoms, or experienced activity limitation due to asthma. They also reported the number of symptom-free days within the previous 2 weeks, defined as the number of 24 h periods without any asthma symptoms.

Children independently completed a shorter survey assessment before the initial and 1-month follow-up visits. We asked children to report asthma responsibility using the same 9-item survey posed to caregivers. We also measured self-efficacy using the Child Asthma Medication Self-Efficacy scale, a 14-question survey designed for young children and comparable to the 13-question panel posed to caregivers (38). The child self-efficacy score was generated by averaging the numeric responses across all items; a higher score indicates greater child self-efficacy with using asthma medications (range 1–5).

Analysis

We used descriptive statistics to report participant characteristics, and conducted a descriptive analysis of feasibility using process measures documented by nurses in the EMR. Next, we performed a series of pre-post analyses to examine the preliminary effectiveness of the intervention on caregivers and children. Due to the relatively small sample size, we did not assume that data would be normally distributed and therefore decided to use an appropriate non-parametric test.

Non-parametric tests additionally reduce the impact of outlier data when analyzing results. All preliminary outcomes of interest (e.g. responsibility, self-efficacy, caregiver quality of life, and caregiver-reported symptoms) involve continuous data. Accordingly, we used Wilcoxon signed rank tests for comparisons of non-parametric paired continuous data. Each of these analyses were completed within subject, comparing responses at the 1-month follow-up (caregiver and child) and final follow-up (caregiver only) with baseline measurements. All analyses were performed using SPSS (version 25.0). An exact 2-sided alpha <0.05 was considered statistically significant.

Results

We enrolled 22 caregiver/child dyads into the pilot study between June-December 2018. An additional 5 children met eligibility criteria at the time of an appointment, but caregivers were unable to stay in clinic for the additional time required to complete the consent, baseline assessment, and nursing education. One child who met criteria did not provide assent, and so was not enrolled. The average ages of enrolled children and caregivers were 10.2 years and 35.0 years, respectively. Most children were male, all caregivers were female, and most participants identified as Black. All children had public health insurance per inclusion criteria. Additional participant characteristics are displayed in Table 1. Eighteen dyads completed the 1-month follow-up assessment, with a median

Table 1. Participant demographics^a (N = 22).

	Child	Caregiver
Age	10.2 (1.8)	35.0 (6.7)
Gender		
Male	15 (68%)	0 (0%)
Female	7 (32%)	22 (100%)
Ethnicity		
Hispanic	5 (23%)	4 (18%)
Race		
White	3 (14%)	3 (14%)
Black	14 (64%)	14 (64%)
Other	4 (18%)	4 (18%)
Prefer to not answer	1 (4%)	1 (4%)
Insurance		
Medicaid/Managed Care	22 (100%)	
Discontinuous coverage (past 12 months)	2 (9%)	
Lives in a home with ≥1 smoker	7 (32%)	
Relationship status		
Single		15 (75%)
Domestic partnership		2 (10%)
Married		2 (10%)
Separated/divorced/widowed		1 (5%)
Education level		
< High school graduation		8 (40%)
High school graduate/GED		7 (35%)
Tech school/some college		4 (20%)
College graduate		1 (5%)

^aReported as n (%) or mean (SD).

Table 2. Implementation of planned intervention components.

	Initial visit	1 month follow-up
Provider/pharmacy tasks	(N = 22)	(N = 18)
Written asthma action plan completed	21 (95%)	14 (78%)
Controller medication(s) prescribed	18 (82%)	10 (56%)
Asthma prescriptions sent to in-house pharmacy	18 (82%)	10 (56%)
Asthma medications delivered to clinic	18 (82%)	10 (56%)
Nurse tasks	(N = 22)	(N = 17)
"Let's Take Control of Asthma" reviewed	20 (91%)	15 (88%)
Written asthma action plan reviewed	21 (95%)	14 (82%)
Colored stickers applied to medications in clinic	18 (82%)	10 (59%)
Spacer given to family in clinic	22 (100%)	14 (82%)
Metered-dose inhaler (MDI) and spacer technique reviewed	22 (100%)	17 (100%)
Caregiver and patient both demonstrated correct technique for MDI and spacer	20 (91%)	17 (100%)
Shared responsibility for asthma medications discussed	22 (100%)	17 (100%)
Caregiver and patient stated understanding of teaching	22 (100%)	17 (100%)
Median time spent on teaching (min)	25.0 (20.0-30.0)	15.0 (10.0-17.5)

^aReported as n (%) or median (IQR).

Table 3. Bivariate comparisons of preliminary outcome measures with initial visit^a.

	Initial visit (N = 22)	1 month follow-up (N = 18)	Final follow-up (N = 15)
Child			
Responsibility score (range: 9–27)	14.0 (11.8–16.3)	15.0 (13.0–19.3)**	†
Self-Efficacy score (range: 1–5)	3.9 (3.4–4.3)	4.3 (4.0–4.6)*	†
Caregiver			
Responsibility score (range: 9–27)	13.0 (9.8–10.3)	13.0 (11.8–14.3)	14.0 (11.0–16.0)
Self-Efficacy score (range: 1–5)	4.3 (3.9–4.8)	4.5 (4.4–4.8)**	4.8 (4.5–4.9)*
Quality of Life score (range: 1–7)	5.8 (4.6–6.4)	†	6.8 (6.6–7.0)***
Reported symptoms (2 weeks)			
Symptom-free days	5.5 (0.0–10.0)	7.0 (2.0–12.0)	14.0 (10.0–14.0)***
Days with symptoms	5.0 (2.0–5.0)	4.0 (2.8–4.5)**	0.0 (0.0–2.0)***
Nights with symptoms	3.0 (0.8–9.0)	4.0 (0.8–10.5)	0.0 (0.0–2.0)**
Days with activity limitation	5.5 (2.0–11.0)	3.5 (1.8–8.0)*	0.0 (0.0–1.0)**
Rescue medication use (days)	3.0 (2.0–7.3)	4.0 (1.8–10.5)	0.0 (0.0–3.0)**

^aReported as median (IQR).

* $P \leq 0.05$; ** $P \leq 0.01$; *** $P \leq 0.001$.

†Not assessed.

(interquartile range; IQR) time for follow-up of 36 days (31–62); 15 caregivers completed final assessments with a median follow-up time after the 1-month clinic visit of 98 days (98–134).

Feasibility

Implementation rates for key process measures are shown in Table 2. Overall, there was a high level of fidelity to intervention delivery. During the initial visit, we observed the lowest rates of task completion among provider or pharmacy dependent tasks such as controller medication prescriptions (82%) and medication delivery to clinic (82%). Colored stickers were applied to all medications delivered to clinic; all other nurse-specific tasks had completion rates >90%. Just over half of providers prescribed medications at the 1-month follow-up visit; some caregivers indicated that refills were not needed. Although nursing documentation was not completed for one subject at follow-up, high completion rates of nurse tasks were similarly documented at this visit.

We initially trained four full-time pediatric registered nurses to deliver the intervention during an

hour-long lunch session. We aimed to limit demands on nursing time at the outset by only scheduling one baseline or 1-month follow-up visit per half-day clinic session. Within the first two months (June–July 2018), we encountered four instances in which a patient met eligibility criteria but no nurse was available to provide the intervention. After training two more nurses in late July, at least one nurse was always available to deliver the intervention. The median time required for intervention delivery was 25 min at the initial visit and 15 min at 1-month follow-up.

Preliminary effectiveness

Child-reported responsibility for asthma management increased from a median (IQR) score of 14.0 (11.8–16.3) in the initial assessment to 15.0 (13.0–19.3) at 1 month ($P = 0.005$); no significant differences in caregiver-reported responsibility for asthma management were seen at either the 1 month or final follow-up assessments (Table 3). We observed significant improvements in self-efficacy with asthma medication use among both children and caregivers.

Child self-efficacy scores increased from 3.9 (3.4–4.3) at baseline to 4.3 (4.0–4.6) at 1 month ($P=0.02$). The median caregiver self-efficacy score at baseline was 4.3 (3.9–4.8), increasing to 4.5 (4.4–4.8) at 1 month ($P=0.009$) and 4.8 (4.5–4.9) at final follow-up ($P=0.02$). Between baseline and final follow-up assessments, caregiver asthma-related quality of life increased from 5.8 (4.6–6.4) to 6.8 (6.6–7.0) ($P<0.001$). Significant reductions in the number of caregiver-reported daytime symptoms and days with activity limitation were observed at the first follow-up, with significant improvements in all symptom measures reported at the final follow-up.

Discussion

Prevalent gaps in the delivery of guideline-based asthma care lead to missed opportunities for children and caregivers to receive necessary home management education. This intervention was designed to circumvent provider time barriers by partnering with pediatric nurses to deliver asthma education after the provider visit concludes, an approach that has been associated with improved asthma outcomes (40). We incorporated the use of visual teaching materials and teach-back methods when possible, to facilitate learning among both children developing literacy skills and caregivers with potentially disparate health literacy levels. Colored medication labels were also used as a visual teaching aid. Patients and caregivers often identify asthma medications by describing device color (27, 41, 42), yet inhaled rescue and controller medications can be manufactured with the same color. Accordingly, the intervention featured the labeling of medications with colored stickers to help dyads reliably differentiate between controller and rescue therapy.

In this pilot study, we demonstrated that nurse-delivered asthma education can successfully engage caregivers and children as partners in home asthma management. The intervention was implemented with high-fidelity in a busy clinical setting: most patients received all planned educational components at both the initial and 1 month visits. Completion rates were slightly lower for tasks requiring provider contributions (i.e. review of updated action plans, application of colored stickers to medications that were prescribed and delivered to the clinic). Fewer prescriptions were sent to the pharmacy for clinic delivery at the 1-month visit, in part due to families reporting they didn't need refills. With the support of clinic leadership, at least one of the six trained pediatric registered nurses was available to provide asthma education each weekday morning and afternoon. The time spent on

education at the initial and 1 month visits approximates the previously established 15- and 30-min blocks of time for which our nurses can bill for patient education, removing a potential financial barrier of lost non-reimbursed time in clinic when providing this type of service.

By using picture-based materials, teach-back methods, and colored stickers to differentiate rescue and controller medications, this intervention was designed to facilitate the sharing of important asthma management concepts with learners from different literacy backgrounds. Preliminary outcomes are encouraging. Self-efficacy in using asthma medications improved among both children and caregivers at each assessment period, with child-reported responsibility also increasing at the 1-month follow-up. The lack of a corresponding change in caregiver-reported responsibility may suggest a steady presence of caregiver supervision as children become more involved in their own care. This is worth noting, since continued caregiver involvement has been identified as a protective factor in the management of chronic childhood diseases (37). We also observed significant improvements in caregiver-reported symptoms over subsequent follow-ups, and in caregiver asthma-related quality of life between baseline and final follow-up assessments. The change in caregiver quality of life score between baseline and final follow-up was greater than the previously defined minimally important difference of 0.5 points (39). To our knowledge, clinically important differences have not yet been established for the other continuous outcome scales used in this study.

There are several limitations worth considering. The small convenience sample, while appropriate for a feasibility study, did not provide adequate statistical power and limits generalizability to other populations. Although we did not aim to enroll a representative sample of children from this pediatrics clinic, the percentage of child subjects who were identified by caregivers as having Black race or Hispanic ethnicity approximates our larger clinic population (65% Black, 15% Hispanic). Most children in our clinic (85%) also have public health insurance, which was a requirement for enrollment. The study design featured a quasi-experimental pre-post analysis of a single group, and it is unclear whether observed improvements are attributable to the intervention or other factors. For example, changes in self-efficacy and child responsibility scores may represent social desirability bias. Similarly, it is not clear whether improvements in caregiver-reported symptoms are due to the intervention, a temporal fluctuation in symptoms experienced

by young children with asthma in urban settings (43), or a research participation effect (44). A large-scale randomized trial will be necessary to fully examine intervention outcomes and clinical significance. Finally, this intervention was feasible to implement in a university-associated clinic with an on-site pharmacy. Modifications to the protocol, such as providing dyads with stickers to apply on medications at home with nurse guidance by telephone, may be required for clinics not located near a pharmacy or for insurance plans requiring medication copayments.

Conclusions

This pilot study demonstrates that nurse-delivered asthma education for caregiver/child dyads is feasible to implement in a busy clinic. Although more studies are needed to determine whether observed improvements in preliminary outcomes are replicated in larger samples, this intervention is a compelling, accessible mechanism to help underserved children with uncontrolled asthma receive the outpatient care that they need.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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