

The Role of Patient Navigators in Improving Caregiver Management of Childhood Asthma

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Abstract

Childhood asthma is a significant public health problem in the United States. Barriers to effective asthma management in children include the need for caregivers to identify and manage diverse environmental triggers and promote appropriate use of preventive asthma medications. Although health care providers may introduce asthma treatments and care plans, many providers lack the time and capacity to educate caregivers about asthma in an ongoing, sustained manner. To help address these complexities of asthma care, many providers and caregivers rely on patient navigators (defined as persons who provide patients with a particular set of services and who address barriers to care) (Dohan & Schrag, 2005). Despite growing interest in their value for chronic disease management, researchers and providers know little about how or what benefits patient navigators can provide to caregivers in managing asthma in children. To explore this issue, we conducted a mixed-method evaluation involving focus groups and a survey with caregivers of children with moderate-to-severe asthma who were enrolled in the Merck Childhood Asthma Network Initiative (MCAN). Findings suggest that patient navigators may support children's asthma management by providing individualized treatment plans and hands-on practice, improving caregivers' understanding of environmental triggers and their mitigation, and giving clear, accessible instructions for proper medication management. Study results may help to clarify and further develop the role of patient navigators for the effective management of asthma in children.

Introduction

Childhood asthma is a critical public health problem in the United States (Akinbami, Centers for Disease Control, & Prevention National Center for Health Statistics, 2006; Akinbami et al., 2012; Eder, Ege, & von Mutius, 2006). The condition affects over 6 million children 0 to 17 years of age, and the prevalence of childhood asthma increased steadily at a rate of 1.4 percent annually between 2001 and 2010 (Centers for Disease Control & Prevention, 2013; Moorman et al., 2012). Rates of asthma attacks declined during this time, but only modestly, from 61.7 to 58.3 percent (Moorman et al., 2012). Recent reports on trends of asthma prevalence in children indicate a plateau from 2010 to 2013, though disparities among certain subgroups increased, including increased prevalence for 10-to-17-year-olds, poor children, and children living in the South (Akinbami, Simon, & Rossen, 2016). The findings demonstrate a great need for continued improvement in the management of childhood asthma.

Caregivers must often assume the responsibility for managing childhood asthma. Caregivers of children with asthma need to understand the condition, identify and mitigate environmental triggers, and administer treatments appropriately—or help their child in taking these responsibilities. These tasks are difficult to remember, master, and carry out, however, and for these reasons, they are a major source of poor control of asthma (Akinbami et al., 2006; Modi & Quittner, 2006). Health care providers often lack the time or capacity to effectively coach and counsel caregivers in all the aspects of self-management for chronic illnesses like asthma (Wagner et al., 2001).

To support the complex needs of chronic disease management, many patients, caregivers, and providers rely on patient navigators (Fischer, Sauaia, & Kutner, 2007; Fowler, Steakley, Garcia, Kwok, & Bennett, 2006; Viswanathan et al., 2009). Patient navigators provide patients with a particular set of services and address barriers to care (Dohan & Schrag, 2005). For asthma, patient navigators work with caregivers and their children to provide health education and to address the various responsibilities of and barriers to asthma management. In a 2010

study on patient navigators for minority and poor asthma patients, patient participants identified better asthma management through informational (education) and instrumental (physical) support that a patient navigator provided (Black et al., 2010). Adding to these perceived benefits, provider participants (nurses and physicians) argued that patient navigators may use knowledge of patients' environment and social context to improve the effectiveness of asthma care plans. Overall research on patient navigators suggests that these professionals may augment the role of the health care provider, including provision of access to feasible, cost-effective, and individualized care for caregivers and children with asthma (Black et al., 2010).

The patient navigator's facilitative function complements the goals of the Affordable Care Act (ACA), including the aim of improving population health and the individual patient care experience at reduced cost (Berwick, Nolan, & Whittington, 2008). Patient navigators may also advance the ACA's goal of practicing transformation models, such as the use of Patient Centered Medical Homes (PCMHs) and Accountable Care Organizations (ACOs) that emphasize closely managing high-risk patients and engaging them in care decisions, treatment, and discussions about barriers to adherence (Meyers et al., 2010).

From 2005 to 2009, the Merck Childhood Asthma Network, Inc. (MCAN) implemented evidence-based interventions to mitigate childhood asthma in five project sites: Chicago, Los Angeles, New York City, Philadelphia, and San Juan, Puerto Rico. All intervention communities had both significant pockets of poverty and high asthma morbidity. Each site had unique evidence-based interventions, and the details of these variations are described elsewhere (Malveaux & Butterfoss, 2011; Viswanathan et al., 2011a). Across all sites, however, interventions included established components for quality asthma care, including (1) education on asthma care; (2) control of environmental factors that affect or trigger asthma (e.g., animal dander, pollens); and (3) pharmacologic therapy (e.g., inhaled corticosteroids) (National Heart Lung and Blood Institute, 2007).

Each MCAN project also embraced key elements of successful community-based asthma programs by emphasizing community stakeholder partnerships and addressing or accounting for the physical and social environment (Clark, Lachance, Milanovich, Stoll, & Awad, 2009). Patient navigators were involved in all interventions to facilitate access to high-quality, community-based asthma care and to promote effective self-management. The individuals recruited to the patient navigator position had no formal health background, except in the Los Angeles intervention, which used school nurses. Most patient navigators lived or worked in the targeted communities. They led health education activities (in the clinic, the home, or both), performed environmental assessments of conditions in the home that could trigger or exacerbate asthma symptoms, and linked families to social services and other resources as needed.

Despite research documenting the benefits of patient navigators for chronic disease management, we know little about how these benefits are actually realized, including assisting caregivers with asthma management in children (Crocker et al., 2011; Krieger, Song, & Philby, 2015; Krieger, Takaro, Song, Beaudet, & Edwards, 2009; Perez-Escamilla et al., 2015; Rodday et al., 2015). In this study we aim to help explore this issue by complementing MCAN evaluation findings with caregivers' perceptions of the factors and conditions by which patient navigators support their effective management of their child's asthma. This study addresses the MCAN initiative key evaluation question: Have MCAN programs improved caregiver knowledge of and positive behaviors toward asthma? And with regard to understanding the process behind these changes in knowledge and behavior, we ask: How has the role of the patient navigator in MCAN interventions supported caregivers' capacity to (1) mitigate their children's exposure to environmental triggers and (2) improve medication management? Findings from this study may help to identify key pathways and high-impact points for patient navigators to shape and improve caregivers' understanding and management of children's asthma.

Methods

To investigate how patient navigators may support caregivers' management of their children's asthma, we compared caregiver responses to a common survey with findings from caregiver focus groups conducted across MCAN intervention sites. Our goal was to assess the degree to which caregivers effectively addressed environmental triggers and medication management, and then to understand how patient navigators may have influenced these efforts. This approach follows a convergent parallel mixed-method study design, in which both methods occur concurrently, with the aim of integrating the results in the analyses to more completely understand project outcomes. This mixed-method approach is ideal for the study of complex phenomenon in real-world settings requiring multiple sources and types of data to understand the context of the problem (Creswell & Plano Clark, 2011).

Focus Groups

A two-member team of independent investigators with knowledge of the MCAN initiative conducted six focus groups across the five MCAN communities. Eligible participants were caregivers (usually parents) of children with moderate-to-severe asthma who were enrolled in the MCAN initiative and who participated in an intervention (or program) in one of the five intervention sites. Program staff, including the patient navigator, assisted with recruitment by distributing flyers to potential participants and directing them to the investigative team via a toll-free number if they wished to join a focus group.

Each focus group lasted approximately 90 minutes. The sessions were conducted between March and April 2009 and in August 2009, in the same facilities that were used for intervention activities. Three of the six focus groups were conducted in Spanish. Before starting each focus group discussion, the moderator read aloud the informed consent form, which included the objectives of the focus group, the rights of participants, the risks and benefits of participation, confidentiality protections, and data use. All respondents gave oral permission for digitally recording the sessions. RTI International's

Institutional Review Board (IRB) reviewed and approved the study protocol. In two sites, a local IRB also approved the protocol.

To facilitate the focus group discussions, we developed a semi-structured guide (see Appendix A) using multiple theories of health behavior change (Green & Frankish, 1994), and organized around the following themes:

- Priority information needs: What information and knowledge were caregivers seeking through the program?
- Barriers: What was the most difficult aspect of learning to manage the child's asthma?
- Relevance: What aspects of the program were most effective for the child?
- Individualization: What aspects of the program were changed to be more effective for the child?
- Feedback: What sources of feedback did parents receive; how did they know they were managing the medications, triggers, and symptoms appropriately?

For the three focus groups conducted in Spanish, we translated focus group guides in two steps: (1) bilingual members of the investigative team translated and back-translated the instrument, and (2) the local project staff on site reviewed these instruments and tailored words, terms, and jargon to the local Spanish dialect (Puerto Rican, Dominican, and Mexican).

Focus Group Analysis

Our team developed an initial coding framework a priori based on the focus group guide, including codes and definitions for each of the five identified themes: (1) priority information, (2) barriers, (3) relevance, (4) individualization, and (5) feedback. Study analysts were trained in the framework and, following review of audio files from each focus group, they systematically applied the framework to create coding memos based on the study research agenda. They organized these memos using NVivo qualitative data analysis software (QSR International Pty Ltd., 2010). A senior team member then reviewed each transcript to ensure that coding adhered to the established definitions and was consistent within and across transcripts. The analysts and senior

team members discussed coding discrepancies and adjusted the coding agreed upon by the team.

Survey

Because the MCAN interventions shared a number of similar outcomes, the MCAN initiative worked collectively to create a common survey instrument (see Appendix B) from previously validated questions, primarily the National Cooperative Inner-City Asthma Study (NCICAS) (Evans et al., 1999) and the sites' existing instruments. The common survey instrument contained 14 questions about symptom severity, knowledge, and behaviors related to asthma management. The analysis presented here used two open-field questions (items 2 and 13) about current "every day" or "as needed" asthma medication use (including over-the-counter and prescription) and trigger reduction activities (e.g., increased dusting, eliminating environmental tobacco smoke, removing stuffed animals from the home).

The survey was administered on a rolling basis between 2007 and 2010 at the time children were enrolled in the project (baseline) and at 6- and 12-month follow-up interviews. For this analysis, we use only data from baseline and the 12-month follow-up to control for seasonality. Although everyone agreed to a set of common questions, the sites administered the questions in different ways: as a stand-alone instrument or incorporated into other instruments the site was already using. Although baseline interviews were always conducted in person, follow-up interviews took place in person or by phone. Of 1,130 baseline interviews, 724 participants (64 percent) also completed the 12-month follow-up interview. Previously published work (Viswanathan et al., 2011b) provides a full description of the survey methods.

Survey Analysis

Two analysts reviewed all written responses, grouped them by similar response, created a description of similarly grouped responses, assigned each grouped response an associated numeric code, and then dually reviewed each code assignment to ensure consistency. The analysts generated descriptive summaries of

the coded data using univariate statistics with Stata software 11 (Stata Corp LP, 2009).

Results

Description of Caregivers

We conducted six focus groups (Table 1) with 51 caregivers of children who had moderate-to-severe asthma. Bilingual members of the evaluation team conducted three of these focus groups (in Los Angeles, New York City, and San Juan) in Spanish. The range of intervention participation varied from just a few weeks to more than 2 years. Across sites, 40 percent of the participants had received services for 1 year or more. In three groups, all the participants had received at least two home visits by the time the focus group was held.

Across the five intervention sites, focus group participants identified intervention benefits related to patient navigators and the effective management of their children's asthma. We organized these benefits according to their impact on two main facets of effective asthma self-management: enhanced environmental trigger identification and management and appropriate medication management.

Table 1. Merck Childhood Asthma Network, Inc. (MCAN) focus group characteristics

Site	Number of focus groups	Number of participants	Minimum number of home visits	Time with the program	With the program 1 year +
Chicago	1	11	2	5 months to 2 years	5
Los Angeles	2	15	2	1 month to 2 years	7
New York City	1	7	1	2 weeks to 1 year	4
Philadelphia	1	8	2	6 months to 2.5 years	4
San Juan, Puerto Rico	1	10	1	6 to 11 months	n/a*

* Program had been operational for less than 1 year at time of focus group. n/a = not applicable.

Enhance Trigger Identification and Management

When they started the program, the majority of caregivers in the focus groups said they wanted to know more about preventing and controlling asthma. They also reported a fair understanding of asthma triggers for their child before they started the program, and noted the role of cigarette smoke, carpets, dust, fumes, pets, pollen, stuffed animals, pests, pollution, and mold. Despite this reported awareness of asthma triggers, however, survey findings at baseline showed low percentages of mitigation for pests (9 percent), feathered or furry animals (18 percent), and strong odors (13 percent). A quarter of the caregivers tried to reduce environmental tobacco smoke (24 percent) and half (49 percent) reported dusting (Table 2).

Table 2. Percentage of households reporting trigger reduction activities, by type, at baseline, 6-, and 12-month follow-up

Trigger type	Sample size (baseline)	Percent	Sample size (12-month follow-up)	Percent
Environmental tobacco smoke				
No	548	75.69	583	80.52
Yes	176	24.31	141	19.48
	724		724	
House dust (cleaning)				
No	372	51.38	159	21.96
Yes	352	48.62	565	78.04
	724		724	
Moisture in the home				
No	691	95.44	654	90.33
Yes	33	4.56	70	9.67
	724		724	
Pests (roaches, rodents, etc.)				
No	658	90.88	619	85.50
Yes	66	9.12	105	14.50
	724		724	
Feathered or furry animals				
No	596	82.32	667	92.13
Yes	128	17.68	57	7.87
	724		724	

(continued)

Table 2. Percentage of households reporting trigger reduction activities, by type, at baseline, 6-, and 12-month follow-up (continued)

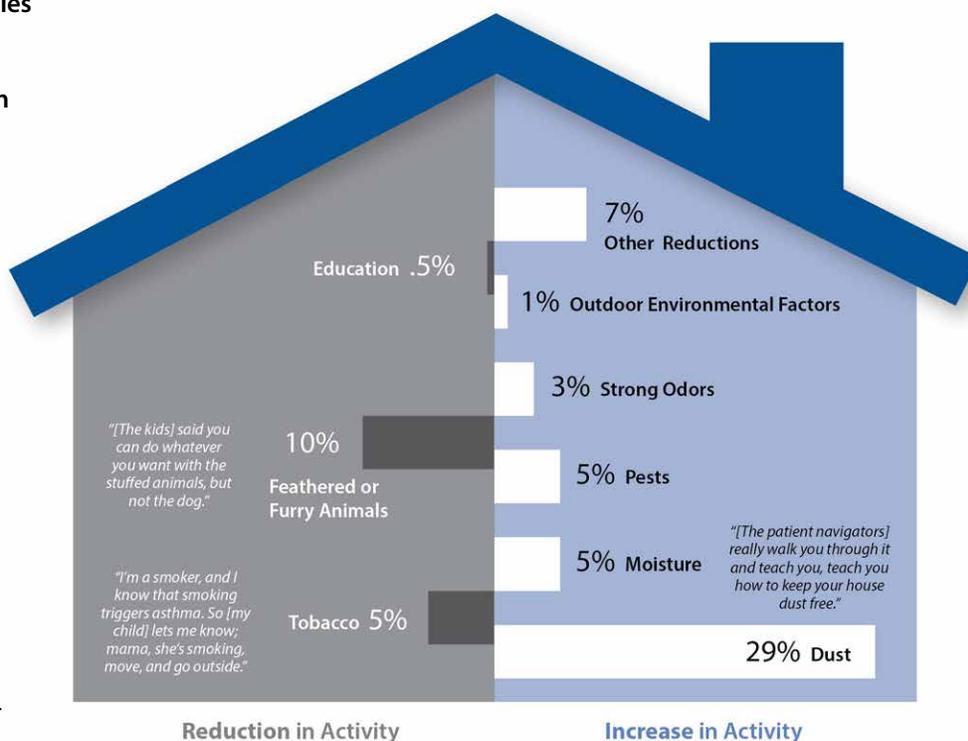
Trigger type	Sample size (baseline)	Percent	Sample size (12-month follow-up)	Percent
Strong odors				
No	633	87.43	608	83.98
Yes	91	12.57	116	16.02
	724		724	
Outdoor environmental factors				
No	698	96.41	689	95.17
Yes	26	3.59	35	4.83
	724		724	
Education				
No	723	99.86	724	100.00
Yes	1	0.14	0	0.00
	724		724	
Other reductions				
No	633	87.43	585	80.80
Yes	91	12.57	139	19.20
	724		724	

Source: Merck Childhood Asthma Network, Inc. (MCAN) Common Data Elements Survey.

Focus group participants reported that learning to better understand and address triggers of their children’s asthma were the most important benefits of the MCAN intervention and access to the patient navigator. They found that the greatest improvement in their children’s symptoms resulted from regular dusting and use of asthma-friendly cleaning techniques and products; removal of stuffed animals; removal of carpets and pests from the home; and elimination of perfumes and other sources of strong odors. These focus group findings are consistent with survey data presented in the right side of Figure 1. Specifically, caregivers reported percentage point increases between baseline and 12-month follow-up in dusting and cleaning (29 percent); removal of moisture and pests (5 percent); and reduction of strong odors (3 percent).

Despite improvements in addressing certain triggers following program participation, caregivers described difficulty in reducing or eliminating other triggers, including removing feathered or furry animals and smoke from the home (see Figure 1, left side). Some participants said that reducing exposure to feathered or furry animals meant giving away a pet, an option

Figure 1. Percentage point change in activities to reduce triggers to asthma between baseline and 12-month follow-up



Data sources: MCAN Common Data Elements Survey and parent findings.

Other reductions include: stuffed animals, carpets, outdoor play and sports, outdoor environmental factors (e.g., pollen, pollution), mold, strong odors (e.g., perfume).

"[The kids] said you can do whatever you want with the stuffed animals, but not the dog."

"I'm a smoker, and I know that smoking triggers asthma. So [my child] lets me know; mama, she's smoking, move, and go outside."

"[The patient navigators] really walk you through it and teach you, teach you how to keep your house dust free."

their children rejected. The difficulty of eliminating pets described by caregivers in the focus group is reflected in a decline in the removal of feathered and furry animals (10 percent) in the survey data.

Reducing exposures to animals and environmental smoke could be one-time events and might not be reported again in subsequent follow-up periods. However, the open-field item capturing trigger activities did not contain a “Not applicable” response so we were not able to ascertain whether they were actually one-time activities.

Promote Appropriate Medication Management

Before the intervention, caregivers reported that they did not get proper instruction and guidance on using medication and were confused about appropriate dosage and use of inhalers and spacers. In focus group discussions, however, caregivers reported that the intervention helped to address this challenge, largely via instruction from patient navigators on how to administer their child’s medications. These improvements in asthma management found in the focus groups are mirrored in the broader survey findings of medication management presented elsewhere (Mansfield et al., 2011).

Caregivers found their physicians’ instructions about medication management confusing and difficult to follow. Accordingly, the focus group participants strongly agreed that having the patient navigator explain the physician’s instructions and medication regimen was critical to applying what they had learned. One parent added that the home health visits were more important than their visits with their doctor, and the group expressed agreement.

Focus group participants further elaborated on the value of patient navigators by describing how the relationship afforded direct and personal attention and, therefore, an opportunity for caregivers to tailor the information specifically to their children’s conditions. Participants especially liked demonstrations of how to use and clean asthma supplies, which gave them confidence in managing their child’s asthma effectively. Caregivers’ perceptions that they learned to use medications

more effectively and gained greater confidence could be seen in the broader survey results of Mansfield et al. That analysis found a statistically significant increase in self-confidence scores over a 12-month period, with more than 50 percent of caregivers reporting increased confidence scores (Mansfield et al., 2011).

In addition to supporting caregivers in personal and day-to-day asthma management, participants also described the patient navigator’s role in counseling them to accept and treat asthma as a chronic and potentially lifelong condition. Prior to participation in MCAN, many caregivers gave medications to their children only when they became sick, choosing to discontinue treatment on seeing improvement or side effects. By engaging with patient navigators who helped them understand the role of controller medications, caregivers felt they achieved a key milestone in more effective asthma management practice. Accordingly, in transitioning from a short-to long-term approach to asthma management, the mean number of days of quick-relief medication use (in the last 14 days) dropped (2.49 to 0.85 days), while the percentage of the sample reporting use of a daily controller showed a small but statistically significant increase for the sample as a whole (from 53 percent at baseline to 57 percent after 12 months) (Mansfield et al., 2011).

Moreover, caregivers reported differences in long-term asthma management depending on whether a child had been recently hospitalized. Specifically, the biggest increase in use of a daily asthma control medication occurred in the subset of children who were hospitalized in the 12 months before the baseline survey and were not on a daily controller at baseline (42 percent of these children were using a daily controller after 12 months). This finding was offset by a decrease in the use of daily controllers by children who were not hospitalized in the year before the baseline survey (20 percent fewer were taking a daily controller after 12 months) (Mansfield et al., 2011).

Discussion

In this study, we found that caregivers described positive experiences with their patient navigators and attributed these relationships, in part, to reported increases in trigger reduction activities and treatment adherence, as well as to improvements in managing their children's health and well-being in relation to asthma. These findings align with previous research on the value of patient navigation for patients with chronic disease, including improved asthma control and quality of life for children and adults (Crocker et al., 2011; Krieger et al., 2015; Krieger et al., 2009), reduced disparities in adult cancer diagnosis and care (Perez-Escamilla et al., 2015), and improved blood-glucose control for Latino adults with type 2 diabetes (Rodday et al., 2015). Apart from these benefits for pediatric asthma care, however, we did not see across-the-board improvements in all trigger and medication-related practices.

Focus group findings expanded on previous research to consider the perceived processes by which patient navigation may better support children and caregivers in asthma care. Specifically, findings revealed that caregivers perceive that individualization, through a patient navigator, is important for them to understand and adhere to their children's recommended treatment plan. The patient navigator's ability to demonstrate the use of the supplies, answer questions, and provide ongoing feedback, guidance, and encouragement allowed caregivers to learn medication management skills at their own pace. The reductions in quick-relief medication use and increases in daily controller medication use, particularly among the sickest children (those recently hospitalized), may suggest that caregivers were harnessing their newfound knowledge and self-efficacy acquired through these navigators. The drop in daily controller use among healthier children (those not recently hospitalized), however, was unexpected. An explanation for this finding may be that these children reached a point where a daily controller was no longer necessary. This explanation seems the most plausible, considering that this group of children also experienced fewer symptoms.

Over the period of the study, the percentage of caregivers attempting to address certain environmental triggers, such as tobacco smoke and feathered and furry animals, actually declined. By complementing survey results with focus group data, we infer that some of this decline may be due to what caregivers described as difficulty in reducing their child's exposure to smoke and pets and/or adoption of alternative and unmeasured methods to mitigate the triggers (e.g., smoking outside the home vs. quitting smoking altogether). Focus group findings also suggest that caregivers who could address smoking and pets may have done so prior to the program, while those who could not may have focused on other "feasible" trigger reductions, such as dusting. Given that one may have to quit an addiction or give up a family pet, reducing exposure to environmental smoke and feathered and furry animals may be much more difficult than dusting and washing sheets. Accordingly, these findings are not surprising. For individuals who achieved these actions, a lack of further reported decline in these behaviors would be expected; dusting requires ongoing action whereas quitting smoking or removing a pet would more likely be implemented in the shorter term or as a one-time event. As such, no further declines in these behaviors would have been reported.

Overall, mixed success with environmental trigger reduction underscores the complex etiology of asthma. Because few known universal triggers exist, a general mitigation approach may both miss specific triggers and include unnecessary and taxing requirements for a given individual (Dick, Doust, Cowie, Ayres, & Turner, 2014). For example, feathered and furry animals are not a universal asthma trigger; thus, families who experience asthma relief through other means (e.g., washing sheets) may have less incentive or need to remove the family pet. Although a customized care plan was found to be more effective in treating asthma in children (Evans et al., 1999; Morgan et al., 2004), the process of individualization, such as undergoing nonroutine allergy tests, can involve large physical, financial, and informational hurdles for caregivers. Our findings suggest that even in a low-resource setting, a patient navigator may offer caregivers a way to avoid these burdens and still individualize a trigger-

education intervention. Through home visits, patient navigators can observe the environment in which the child lives, enabling them to offer and clearly explain suggestions for remediation specific to that environment. Through sustained follow-up with the family, the patient navigator can assess whether those suggestions are feasible and effective, and can offer alternative strategies if they are not.

The concept of “support for navigating the knowledge landscape” offers one insight into why individualization may be important. This concept acknowledges that patient needs and preferences are dynamic; therefore, how information is presented to caregivers is a continuous, flexible process (Kazimierczak et al., 2013).

Limitations

The main limitation of the focus groups and survey was the lack of a control group; consequently, we cannot draw any causal inferences about the patient navigator’s role on trigger mitigation and medication adherence. We were also unable to recruit focus group participants in a completely unbiased manner. The focus group participants who agreed to participate may have been those most satisfied with the program or those that program staff approached. Those who were least satisfied may have dropped out of the program altogether and would have been unrepresented in both the focus group and survey data.

Another limitation was that survey data were not collected uniformly across sites although the items themselves were the same. Some used in-person interviews and others used telephone interviews. In addition, and as described above, the MCAN sites served different populations in five highly distinct urban settings and employed different intervention approaches that they thought appropriate for their communities. These variations in data collection method and intervention approach may have affected participant experiences, responses, and response rate.

Conclusion

The results presented in this study, although exploratory, suggest that patient navigators help caregivers understand and manage their child’s asthma. The usefulness of patient navigators may lie in their ability to troubleshoot and individualize the asthma management strategy. Families living in a changing (and often chaotic) environment and coping with a highly dynamic, chronic condition such as asthma could benefit from information provision that is correspondingly adaptive and responsive. Tailoring information to the family’s needs also reinforces the concept of patient-centered care. The efficacy of patient navigators remains an open question; therefore, understanding the attributes of patient navigation and the causal pathway to the desired improvements in asthma management are important for future program design and implementation.

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Appendix A. Semistructured Focus Group Guide

Draft Parent Focus Group Guide

Warm-up

Introductions: First names only, your children's names, who has asthma

Tell me about your involvement with [NAME OF THE PROGRAM]. [Probe for when, how long, how they found out about it]

Tell me about [NAME OF THE PROGRAM] activities that your family has been involved in.

Access and Quality of Asthma Care

How do you feel about the health care he/she receives?

What do you need to get your child the health care she/he needs?

- Counseling on how to apply for Medicaid?
- Mechanism for making appointments?
- Appointment reminders?
- Missed appointment follow-ups?

What kind of help was [NAME OF THE PROGRAM] able to give you to help your child get asthma care?

Principle of Educational Diagnosis

What do you think was causing your child's asthma?

What made it hard for you to help your child control their asthma?

- probe for difficulties sticking with treatments
- probe for difficulties with triggers especially pets

Principle of Hierarchy/Cumulative Learning

When you started [NAME OF THE PROGRAM] what did you learn or talk about first?

What came after that?

[Listing exercise] What are the things you have learned from [NAME OF THE PROGRAM]? Have they been helpful in managing your child's asthma? Why?

Did [NAME OF THE PROGRAM] suggest ideas that did not work for you? Why?

What more would you like to know about managing asthma?

What suggestions would you have for educating parents about asthma?

Draft Parent Focus Group Guide (*continued*)

Principle of Participation/Empowerment

How difficult or easy is it for you to manage your child's asthma now? What kinds of things do you do?

- probe for action on medication use, peak flow meter use, trigger reduction in the home, smoking cessation, etc.

Has this changed since you began the program?

- probe for self-efficacy to assess early symptoms
- probe for self-efficacy re: peak flow meter use

When you talk with the doctor about your asthma, what do you talk about?

- probe for whether the doctor is soliciting their beliefs, needs, opinions, ideas

When you talk with the child about your asthma, what do you talk about?

- probe for whether they are soliciting the child's beliefs, needs, opinions, ideas

Principle of Individualization

Think back to when you first started with [NAME OF THE PROGRAM] and were trying to follow the recommendations for your child's asthma. Did you notice an immediate improvement?

- if no, what had to change to make the recommendations and treatment work?
- probe for whether the intervention regiment was being tailored

Principle of Feedback

When you were learning to control your child's asthma, how did you know if you were doing it right? Who did you go to for help?

- probe to assess if they were getting feedback from parent, doctor, asthma counselor

How do you provide feedback on the education you receive? What kinds of things do you provide feedback on?

Principle of Relevance

Tell me about the asthma materials you have received from [NAME OF THE PROGRAM]. What did you think about them [probe for what they did or did not like]?

How many of you need or have used translation services? What did you think about them?

Wrap-Up

How has the project helped you?

How do you think you have been affected [NAME OF THE PROGRAM]? [Probes: What did you learn? What do you do differently now?]

What changes would you make, if any, to [NAME OF THE PROGRAM]?

Is there anything else you think we should know about [NAME OF THE PROGRAM] that we didn't ask?

Appendix B. MCAN Survey Instrument

MCAN Common Data Elements

WE WOULD LIKE TO ASK YOU A FEW QUESTIONS ABOUT MEDICATIONS [CHILD'S NAME] MAY TAKE FOR [HIS/HER] ASTHMA. THESE COULD BE OVER-THE-COUNTER MEDICATIONS OR A DOCTOR MAY HAVE PRESCRIBED OR GIVEN THEM TO YOU FOR [CHILD'S NAME] ASTHMA.

1 Does [CHILD'S NAME] currently take medication for asthma? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

- 1** Yes [GO TO QUESTION 2]
- 2** No [SKIP TO QUESTION 4]
- 994** Don't Know [SKIP TO QUESTION 4]
- 997** Refused [SKIP TO QUESTION 4]

2. Please tell us the names of those medications and whether it is taken every day or as needed: [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT; ADD MORE LINES IF CHILD TAKES MORE THAN SIX (6) MEDICATIONS FOR ASTHMA]

[PROMPT: THESE COULD BE OVER-THE-COUNTER OR DOCTOR PRESCRIBED MEDICATIONS]

[PROMPT: IF RESPONDENT ANSWERS INHALER, ASK IF THEY KNOW THE NAME OF THE INHALER]

- | | | | | | |
|--------------------------------|------|---|---|--|---|
| 2.1M Medication 1 _____ | 2.1T | 1 <input type="checkbox"/> Every day | 2 <input type="checkbox"/> As needed | 994 <input type="checkbox"/> Don't Know | 997 <input type="checkbox"/> Refused |
| 2.2M Medication 2 _____ | 2.2T | 1 <input type="checkbox"/> Every day | 2 <input type="checkbox"/> As needed | 994 <input type="checkbox"/> Don't Know | 997 <input type="checkbox"/> Refused |
| 2.3M Medication 3 _____ | 2.3T | 1 <input type="checkbox"/> Every day | 2 <input type="checkbox"/> As needed | 994 <input type="checkbox"/> Don't Know | 997 <input type="checkbox"/> Refused |
| 2.4M Medication 4 _____ | 2.4T | 1 <input type="checkbox"/> Every day | 2 <input type="checkbox"/> As needed | 994 <input type="checkbox"/> Don't Know | 997 <input type="checkbox"/> Refused |
| 2.5M Medication 5 _____ | 2.5T | 1 <input type="checkbox"/> Every day | 2 <input type="checkbox"/> As needed | 994 <input type="checkbox"/> Don't Know | 997 <input type="checkbox"/> Refused |
| 2.6M Medication 6 _____ | 2.6T | 1 <input type="checkbox"/> Every day | 2 <input type="checkbox"/> As needed | 994 <input type="checkbox"/> Don't Know | 997 <input type="checkbox"/> Refused |

- 994** Don't Know
- 997** Refused

[PROMPT: ASK RESPONDENT IF THERE ARE ANY ADDITIONAL MEDICATIONS THEY CAN THINK OF BEFORE MOVING ON TO THE NEXT QUESTION]

MCAN Common Data Elements (*continued*)

- 3.** During the past 14 days, how many days did [CHILD'S NAME] use [HIS/HER] quick-relief or rescue medication for asthma, wheezing or tightness in the chest, or cough? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: THINK OF A DAY AS BEING A 24-HOUR PERIOD. IF THE CHILD HAD MULTIPLE EPISODES DURING EITHER THE DAY OR NIGHT OF A 24-HOUR PERIOD, PLEASE COUNT THAT AS ONE (1) DAY]

_____ Days [RANGE 0-14]

992 Does not apply [CHILD DOES NOT TAKE RESCUE MEDICATIONS]

994 Don't Know

997 Refused

- 4.** An asthma action or management plan is a printed form that tells when to increase medicine, when to take other medicine, when to call the doctor for advice, and when to go to the emergency room. Has a doctor or other health professional ever given [CHILD'S NAME] or [CHILD'S NAME]'s parent/caregiver/guardian an asthma management plan? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

1 Yes

2 No

994 Don't Know

997 Refused

NOW WE WANT TO TALK WITH YOU ABOUT HOW ASTHMA AFFECTS YOU AND [CHILD'S NAME] EACH DAY.

THE NEXT FEW QUESTIONS ARE ABOUT [CHILD'S NAME] HEALTH IN THE LAST TWO WEEKS, THAT IS, THE PAST 14 DAYS, SINCE [GIVE RESPONDENT THE DATE 14 DAYS PRIOR TO TODAY]. SOME QUESTIONS ARE ABOUT YOUR CHILD'S ASTHMA DURING THE DAY AND SOME QUESTIONS ARE ABOUT YOUR CHILD'S ASTHMA DURING THE NIGHT.

- 5.** In the last 14 days, how many days did [CHILD'S NAME] have wheezing or tightness in the chest, or cough? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: IF THE CHILD HAD MULTIPLE EPISODES DURING THE DAY, PLEASE COUNT THAT AS ONE (1) DAY]

_____ Days [RANGE 0-14]

994 Don't Know

997 Refused

MCAN Common Data Elements (continued)

6. In the last 14 nights, how many nights did [CHILD'S NAME] wake up because of asthma, wheezing or tightness in the chest, or cough? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: IF THE CHILD HAD MULTIPLE EPISODES DURING THE NIGHT, PLEASE COUNT THAT AS ONE (1) NIGHT]

_____ Nights [RANGE 0-14]

994 Don't Know

997 Refused

7. In the last 14 days, how many days did [CHILD'S NAME] have to slow down or stop [HIS/HER] play or activities because of asthma, wheezing or tightness in the chest, or cough? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: IF THE CHILD HAD TO SLOW DOWN OR STOP HIS PLAY MULTIPLE TIMES IN ONE DAY, PLEASE COUNT THAT AS ONE (1) DAY]

_____ Days [RANGE 0-14]

994 Don't Know

997 Refused

THE NEXT FEW QUESTIONS ARE ABOUT THE PAST YEAR, THAT IS, SINCE [GIVE RESPONDENT THE DATE ONE YEAR PRIOR TO TODAY'S DATE]

8. During the past twelve (12) months, how many days did [CHILD'S NAME] miss school for any reason? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: PLEASE INCLUDE ONLY DAYS WHEN SCHOOL (OR DAYCARE/PRE-SCHOOL, DEPENDING ON AGE OF THE CHILD) WAS IN SESSION]

_____ Days [RANGE 0-365]

992 Does not apply [CHILD NOT IN SCHOOL; SKIP TO QUESTION 10]

994 Don't Know

997 Refused

9. During the past twelve (12) months, how many days did [CHILD'S NAME] miss school due to asthma? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: PLEASE INCLUDE ONLY DAYS WHEN SCHOOL (OR DAYCARE/PRE-SCHOOL, DEPENDING ON AGE OF THE CHILD) WAS IN SESSION]

_____ Days [RANGE 0-365; NUMBER SHOULD NOT EXCEED THE ANSWER IN QUESTION 8]

992 Does not apply [CHILD NOT IN SCHOOL]

994 Don't Know

997 Refused

MCAN Common Data Elements (*continued*)

- 10.** In the past twelve (12) months, how many times has [CHILD'S NAME] been treated in the Emergency Room or ER for asthma (without hospitalization)? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: DO NOT INCLUDE TIMES WHEN YOUR CHILD WAS ADMITTED TO THE HOSPITAL FOR AN OVERNIGHT STAY RIGHT AFTER BEING TREATED AT THE EMERGENCY ROOM OR ER]

_____ Times [RANGE 0-365]

994 Don't Know

997 Refused

- 11.** In the past twelve (12) months, how many times has [CHILD'S NAME] had to stay overnight in a hospital for asthma? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: THIS NUMBER WOULD NOT INCLUDE VISITS TO THE ER THAT DID NOT RESULT IN AN OVERNIGHT HOSPITAL STAY]

_____ Times [RANGE 0-365]

994 Don't Know

997 Refused

NOW I'D LIKE TO ASK YOU ABOUT THINGS YOU MAY HAVE DONE TO MANAGE [CHILD'S NAME] AT HOME. SOME PARENTS FIND THESE THINGS HELPFUL; OTHERS FIND THEY ARE NOT HELPFUL.

- 12.** Asthma triggers are things that may start or set off an asthma attack in your child. Cigarette smoke, pets and dust are triggers that set off asthma attacks in some children. Have you taken any steps to reduce asthma triggers for [CHILD'S NAME] in your home? [ASK OPEN-ENDED, DO NOT READ OPTIONS TO RESPONDENT]

[PROMPT: TRIGGERS MAY ALSO MAKE YOUR CHILD'S ASTHMA WORSE]

1 Yes [GO TO QUESTION 13]

2 No [SKIP TO QUESTION 14]

994 Don't Know [SEE PROMPT BELOW; IF STILL DON'T KNOW, SKIP TO QUESTION 14]

997 Refused [SKIP TO QUESTION 14]

[PROMPT IF ANSWER IS DON'T KNOW: STEPS CAN BE THINGS LIKE DUSTING MORE OFTEN OR NOT ALLOWING SMOKING IN YOUR HOME]

MCAN Common Data Elements (continued)

13. What steps have you taken to reduce asthma triggers in your home? [ASK THIS QUESTION OPEN-ENDED AND SEPARATELY RECORD EACH STEP MENTIONED BY THE RESPONDENT]

1 _____

2 _____

3 _____

4 _____

5 _____

6 _____

7 _____

8 _____

9 _____

10 _____

994 Don't Know

997 Refused

14. I am going to read you a list of options from strongly agree to strongly disagree to answer this next question. How would you rate your agreement with the following statement; I have control over [CHILD's NAME] asthma. [READ OPTIONS TO RESPONDENT AND SELECT APPROPRIATE ANSWER]

1 Strongly agree

2 Agree

3 Disagree

4 Strongly disagree

994 Don't Know [DO NOT READ]

997 Refused [DO NOT READ]

Demographics

1. [CHILD'S NAME] date of birth? [MONTH RANGE 0-12; DAY RANGE 1-31; YEAR RECORDED AS 4 DIGITS]

__ __ / __ __ / __ __ __ __ [E.G., 12/31/1999]

M M/D D/YYYY

994 Don't Know

997 Refused

2. What is [CHILD'S NAME] gender? [NO NEED TO ASK, JUST MARK APPROPRIATE RESPONSE]

1 Male

2 Female

3. What is your relationship to [CHILD'S NAME]? [MOTHER, FATHER, GRANDMOTHER, ETC]

_____ Relationship

994 Don't Know

997 Refused

4. How would you describe [CHILD'S NAME]'s race, nationality, or ethnic background? [ASK OPEN-ENDED AND USE CODES BELOW]

1 Hispanic [IF PERSON SAYS HISPANIC, PROMPT BY READING THROUGH THE OPTIONS: WOULD YOU SAY, PUERTO RICAN? DOMINICAN? MEXICAN? AND USE CODES BELOW]

11 Puerto Rican

12 Dominican

13 Mexican

14 South American

15 Central/Latin American

16 Cuban

17 Other Hispanic

2 Black/African American

3 White

4 Asian

5 Mixed, [SPECIFY] _____

Demographics (*continued*)

6 Native American

7 Other, [SPECIFY] _____

994 Don't Know

997 Refused

[NOTE ON CODING: HISPANIC IS CODED AS 1 IF NO MORE DETAIL IS PROVIDED. PUERTO RICAN IS CODED 11, ETC.]

5. How many people live in your household, including yourself?

[PROMPT: INCLUDE [CHILD'S NAME] AND YOURSELF IN THE COUNT]

_____ People

994 Don't Know

997 Refused

6. How many children live in your household?

[PROMPT: WE ARE ASKING ABOUT CHILDREN LESS THAN 18 YEARS OLD. INCLUDE [CHILD'S NAME] IN THE COUNT]

_____ Children [NOT TO EXCEED ANSWER GIVEN IN QUESTION 5]

994 Don't Know

997 Refused

7. Does [CHILD'S NAME] primary caregiver speak a language other than English at home?

1 Yes [GO TO QUESTION 8]

2 No [SKIP TO QUESTION 9]

994 Don't Know [SKIP TO QUESTION 9]

997 Refused [SKIP TO QUESTION 9]

8. If yes, what language do they speak?

_____ Language

994 Don't Know

997 Refused

Demographics (*continued*)

9. What is the highest degree or level of school [CHILD'S NAME]'s primary caregiver has COMPLETED?

[IF THE QUESTION IS SELF-ADMINISTERED, USE THIS QUESTION. IF THE QUESTION IS ASKED OVER THE PHONE, ALLOW RESPONDENTS TO STOP INTERVIEWERS WHEN THEY HEAR THE CORRECT RESPONSE. IF QUESTION IS ASKED IN-PERSON BY AN INTERVIEWER, CONSIDER USING A SHOWCARD WITH THE OPTIONS LISTED AND ASK THE RESPONDENTS TO POINT TO THEIR CATEGORY]

- 1 Never attended/ kindergarten only
- 2 1st grade
- 3 2nd grade
- 4 3rd grade
- 5 4th grade
- 6 5th grade
- 7 6th grade
- 8 7th grade
- 9 8th grade
- 10 9th grade
- 11 10th grade
- 12 11th grade
- 13 12th grade, NO DIPLOMA
- 14 GED or equivalent
- 15 HIGH SCHOOL GRADUATE – high school DIPLOMA
- 16 Some college credit, but no degree
- 17 Associate degree: occupational, technical, or vocational program
- 18 Associate degree: academic program

Demographics (*continued*)

- 19 Bachelor's degree (for example: BA, AB, BS)
- 20 Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA)
- 21 Professional degree (for example: MD, DDS, DVM, LLB, JD)
- 22 Doctorate degree (for example: PhD, EdD)
- 994 Don't Know
- 997 Refused

[IF THE INCOME QUESTION IS SELF-ADMINISTERED, USE THIS QUESTION. IF THE QUESTION IS ASKED OVER THE PHONE, ALLOW RESPONDENTS TO STOP INTERVIEWERS WHEN THEY HEAR THE CORRECT RESPONSE.]

10. For the last month, what was your total household income from all sources? Include income from everyone in your home. Give amount before taxes and other deductions. If monthly income is unknown, estimate your income per year.

- 1 Less than \$833 per month (less than \$10,000 per year)
- 2 \$834 - \$1,666 per month (\$10,000 - \$19,999 per year)
- 3 \$1,667 - \$2,500 per month (\$20,000 - \$29,999 per year)
- 4 \$2,501 - \$3,333 per month (\$30,000 - \$39,999 per year)
- 5 \$3,334 - \$3,750 per month (\$40,000 - \$49,999 per year)
- 6 More than \$4,166 per month (more than \$50,000 per year)
- 994 Don't Know
- 997 Refused

[IF THE INCOME QUESTION IS ASKED IN PERSON BY AN INTERVIEWER, USE THIS QUESTION AND CONSIDER SHOWING THE TABLE AND ASKING RESPONDENTS TO POINT TO THEIR CATEGORY, THEN ENTER THE INCOME CODE, RATHER THAN THE DOLLAR AMOUNT]

Demographics (*continued*)

- 10.** For the last month, what was the total household income from all sources? Include income from everyone in your home. Please point to the answer closest to your total household income.

Income code _____

994 Don't Know

997 Refused

Monthly	Income Code	Yearly
Less than \$833 per month	1	less than \$10,000 per year
\$834–\$1,666 per month	2	\$10,000–\$19,999 per year
\$1,667–\$2,500 per month	3	\$20,000–\$29,999 per year
\$2,501–\$3,333 per month	4	\$30,000–\$39,999 per year
\$3,334–\$3,750 per month	5	\$40,000–\$49,999 per year
More than \$4,166 per month	6	more than \$50,000 per year

– Include all sources of income

– If monthly income is unknown, estimate income per year

– Give amount before taxes and other deductions.

- 11.** Does child have health or medical insurance?

1 Yes

2 No

994 Don't Know

997 Refused

- 12.** How many years have you lived at your current residence?

1 < 1 year

2 1-2 years

3 3-5 years

4 > 5 years

994 Don't Know

997 Refused

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