Parent Experiences with a Nurse-Supervised Community Health Worker Asthma Home-Visiting Program

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Abstract

Objective: This study seeks to identify helpful components of a nurse-supervised Community Health Worker asthma home-visiting program, obtain feedback from parents and families about their experiences, and receive suggestions for new services that the program could provide.

Methods: Likert scale ratings and semi-structured qualitative interviews were conducted with parents who were selected from a representative sample and previously participated in the program. Five-point Likert scale ratings from 1 (not helpful) to 5 (very helpful) were obtained for 11 program components. Interviews were analyzed using a grounded theory participatory approach. Data were analyzed and themes were identified by two different coders using Dedoose software.

Results: 22 participants were enrolled and 20 participants completed Likert scale ratings and qualitative interviews. Likert scale ratings (mean, [SD]) show that program strengths include asthma education (4.75, [0.55]), supplies (4.65, [0.99]), help with housing conditions (3.94 [1.56], pest management (3.79, [1.69]) and greater access to community resources (3.70, [1.30]). The ratings suggest that families need more help with other social determinants of health, such as school, lack of enough money or food, and mental health and behavioral concerns (3.05, [1.78]). Interviews echoed these ratings and revealed several themes about family and parental stress, children's activity limitations, desire for outreach after the 12-month intervention, a need for help with other social determinants and more emotional support.

Conclusions: This study shows that the program was well received and reveals the importance of addressing social determinants of health and behavioral health concerns.

Introduction

Asthma is one of the leading chronic childhood illnesses with a prevalence as high as 13.9% in Boston, as found in a large study examining asthma rates of school-age children grades K-8 in Massachusetts (1). This prevalence is significantly greater than the national prevalence of 9.4% in 2010 (2) and the Massachusetts state prevalence of 10.9% (1). In Boston, the Community Asthma Initiative (CAI), a nurse-supervised community health worker (CHW) asthma home-visiting program, was implemented in 2005 and has served over 2000 patients in the last 12 years. This program has significantly improved health outcomes through reductions in asthma-related Emergency Department (ED) visits and hospitalizations, and improved quality of life through reductions in missed school days for children and missed workdays for parents (3-5).

The Community Asthma Initiative has a quality improvement model with regular PDSA cycles evaluating outcome data every six months, and patient experiences are elicited regularly from the program's Community/Family Advisory Board. Qualitative evaluations of community-based programs for children with asthma are limited (6). Some qualitative literature sought general feedback from parents/caregivers, healthcare providers and community stakeholders about caring for children with asthma (7-10), but no qualitative evaluations were identified that have obtained feedback and suggestions from parents and family members who participated in an asthma home-visiting program.

This mixed-methods study aims to fill this gap by way of two complementary assessments: 1) a quantitative rating scale was used to evaluate components of the home-visiting model, and **2) qualitative questions were used to identify themes from parent perspectives about the program, including feedback for improvement. A grounded theory participatory approach, in which major themes are constructed based on interview responses (11), was used to**

analyze the responses to the qualitative questions. This study seeks to identify helpful parts of the program, obtain feedback from parents/caregivers and families, and receive suggestions for new services that the program could provide. This paper also highlights the needs of subpopulations, such as parents of children with asthma and other comorbid behavioral or emotional diagnoses.

Methods

CAI Intervention

Children who have asthma and come from low-income families, particularly families of color, often face other challenges including substandard housing, which can exacerbate their asthma, with 84% of CAI families identifying one or more asthma triggers in their homes, including rodents, pets, mold, cockroaches, environmental tobacco smoke and significant clutter (12). Families also face other social determinants of health (social determinants), such as underfunded schools, community violence that reduces opportunities to safely play outside, and food and housing insecurity, which complicate their health and may lead to worse outcomes. Such social determinants have been shown to contribute to racial and ethnic health disparities in asthma (13, 14).

The Community Asthma Initiative (CAI) is a nurse-supervised CHW home-visiting model of care that enrolls patients primarily aged 2-18 years old with asthma-related ED visits, hospitalizations and/or frequent oral corticosteroid courses. The CHW’s are bilingual and bicultural in Spanish or Cape Verdean Creole and Portuguese and the nurse practitioner is bilingual in Spanish. The program aims to provide three home visits, which include asthma education; a review of environmental triggers, a home environmental assessment and a moderate level of remediation, including supplies (HEPA vacuum, dust mite-proof mattress and pillow encasements, and Integrated Pest Management kits); and case management. Case management includes referrals to: 1) the City of Boston Inspectional Services for housing code violations; 2) Medical-Legal Partnership for advocacy related to legal matters, such as housing, immigration, education, family law and benefits, such as Medicaid; 3) child care; 4) free hospital-sponsored swim classes for children with asthma and; 5) after-school activities and summer jobs programs. CAI also connects or re-connects families to primary care as well as subspecialty care and social work as needed. The program is a one-year intervention with approximately 7% of families needing extended services.

Study population and recruitment

Participants were parents/caregivers of children who enrolled in CAI between June 2013 and June 2016, and had at least one completed home visit. **The population that CAI serves is highly mobile, making it difficult to reach families who have not been involved with the program recently; therefore the time frame was restricted to recent years in order to identify participants that were more likely to be reachable.** Out of all families, 225 patients met these criteria and a representative sample of 100 patients was chosen as a random subgroup to be contacted (Figure 1). Between June and December 2017, these 100 families received a letter and 1 to 3 phone calls informing them of the project and inviting them to interview. Each participant who completed the interview received a $20 grocery store gift card by mail. **The demographics of children whose parents/caregivers were interviewed were compared to those whose parents/caregivers declined interviews or were unable to be reached to assess if there were any differences using the appropriate Chi-square or t-tests.**

Study procedure

In-depth semi-structured interview

The semi-structured interviews included questions about 1) participants' experiences with CAI, both during and after the program, 2) suggestions for program improvement, and 3) quantitative ratings to assess program components. The majority of questions were open-ended with prompts as needed to allow for maximum feedback (see Appendix A). Parents/caregivers verbally consented to the interview, recording and use of data, and demographic questions. The Boston Children's Hospital Institutional Review Board (M06-06-0304) approved access to Quality Improvement evaluation data.

Quantitative program ratings

Five-point Likert scale-type questions ranging from 1 (not helpful) to 5 (very helpful) about different parts of the program, including supplies, asthma education, pest management, and assistance with housing conditions, were incorporated into the semi-structured interviews. The comprehensive Interview Schedule is included in Appendix A.

Data collection and management

Interviews were conducted between July and December 2017. Interviews were conducted by the first two authors (the second author is a native Spanish speaker) and another trained interviewer, also a native Spanish speaker. All interviews were conducted by phone and recorded. Each interview was transcribed verbatim by the interviewer. Interviews conducted in Spanish were transcribed in Spanish and subsequently translated to English.

Data analyses and theoretical framework

Qualitative interview data

A grounded theory participatory approach (11, 15) was used to develop the initial codebook through line-by-line open coding, where codes were developed from the data itself. The first author developed the initial codebook and performed primary thematic coding. The second author performed secondary coding using the initial codebook and further identified codes through open coding analysis. Discrepancies were discussed and reconciled. Emerging themes (Figure 2) were then identified using Dedoose (16) software. A code book was developed and analyzed (Appendix B).

Quantitative program ratings

Likert scale scoring of 11 program elements and areas of potential need were collected. The mean and median were calculated for each item, and are presented as mean and standard deviation (SD).

Results

In this study, 22 participants were able to be contacted and agreed to be interviewed (Figure 1) from the 100 randomly selected parents/caregivers. Of these 22 participants, 20 participants completed interviews and 2 participants partially completed interviews, which were all included in analyses. **The study reached saturation when 22 participants were enrolled and the time available for the research assistant ended at that point, so recruitment was not expanded to another randomly selected group.**

The majority of participants were female persons of color with 50% identifying as Hispanic or Latino and 45% identifying as black/African American (Table 1). Roughly a third of participants identified Spanish as their primary language. Participants' ages ranged from 26 to 54 years with an average age of 37.2 years. Most participants had a family income of less than $25,000 at initial program enrollment, and had some high school education (n=6, 27%), graduated from high school or had a GED (n=4, 18%), or had some college or vocational training (n=9, 41%). **The demographics of the 22 children whose parent/guardian was interviewed were compared to those of the 78 children whose parent/guardian were not interviewed and there were no significant differences (Table 2).** The demographic characteristics of the participants and their children were also similar to the demographics of the overall patient population in CAI. Duration of completed interviews ranged from 9 to 51 minutes with an average length of 16 minutes.

Quantitative Program Ratings

Likert scores (mean, [SD]) revealed that participants felt the program was very helpful with asthma education (4.75, [0.55]), supplies (4.65, [0.99]), counseling about the regular use of (4.55, [1.00]) and obtaining of asthma medication (4.61, [0.98]), care coordination (4.47, [0.96]) care in the home setting (4.37, [1.26]) and emotional support (4.30, [1.08]) (Table 3). Assistance with housing conditions, pest management and accessing community resources were helpful at 3.94 [1.56], 3.79 [1.69] and 3.70 [1.30] respectively. The areas of need that scored lowest, which are addressed less systematically in the CAI intervention, were help with other social determinants, such as school, childcare, lack of money or food, legal aid, child behavior, or mental health services (3.05, [1.78]).

Qualitative Interview Themes

Praise for the program

Many parents had a lot of praise for the program. Several parents mentioned that they wished the program had not ended:

> "My personal experience was awesome. I had an awesome woman who came to my home. I mean, I loved it. I really enjoyed the conversations and us talking and making sure that I was up to date on everything and how to make sure I had [my son's] medications and everything." – female, age 36

Many parents mentioned how the supplies helped them to follow through with changes at home to improve their child's asthma:

> "We're still using the vacuum, we're still…using the dust covers, the pillow covers, the mattress covers, so it's still helping me even though I haven't seen anyone from the asthma community…lately." – female, age 34

Some parents mentioned how much their child has improved and how it has changed their family's quality of life:

> "We're so happy. We don't live with fear anymore. We don't have to take so many precautions. We don't have to go on trips with so many medications. We've been on vacation without all the medicines, without the stress of what might happen." – female, age 44

Asthma education

Many parents highlighted the importance of education about their child's asthma:

> "It opened my eyes a lot, gave me a lot of education that even as a nurse…I didn't even realize. Though it's different when your child is the patient…it just helps having the individual person, that one to one…it was a good program." – female, age 31

Many parents mentioned how they learned to clean their homes using the supplies and advice from the program:

> "[The CHW] had let me know a lot of tips on how I can clean the house with vinegar water, just you know natural products, nothing with any type of scent or odor, anything with any chemicals in it that can actually trigger asthma, so she gave me a lot a lot of feedback on that." – female, age 31

Many parents mentioned how their cleaning habits changed because of the program. Many parents now devote particular attention to specific triggers in different seasons:

> "I follow a lot of [advice] from them like I now clean the house several times with vinegar and water after [being in] the program. I don't clean with the Lysol spray, the lady told me Lysol spray is not good. So I pretty much follow that…so things I had learned from them, like making sure I give [my son] a thick wipe down or anything in the summertime so the pollen will not stick on him…[I] wash the clothes, vacuum frequently, and stuff like that." – female, age 31

Emotional support/suggestions for improvement

Many parents praised the program and CHW's for their emotional support:

> "I think the most useful part was the attention I was given…they made me feel like I wasn't alone, that there were people who were interested in my case and that…that there was hope for us with a program like this that could provide the resources to cope with our problem." – female, age 44

Many parents also discussed the importance of their own mental health. Some parents mentioned the importance of support early on in their child's diagnosis:

> "I think parents need to feel that their mental health is important too….with any health problem their child has….if [doctors] go in the room and just suggest if there's any social services they need help…like you said mental health, because [having a child with health problems] could affect a person mentally. You know be sad and depressed and stuff, feeling like they're…alone. 'Cause I feel like that sometimes with my kids…when they go through stuff." – female, age 47

In response to a question about improving the program, many parents suggested workshops or family support groups:

> "Maybe have parent workshops, like get other parents that went through what a family is going through now, so that maybe that person that went through it before can help the other parent understand how to do X, Y and Z, so that they can have support." – female, age 32

Family and parental stress, activity limitations

Most parents discussed the stress of their child's illness and how it has impacted their families. Many parents mentioned how their personal attitudes have changed and their family activities are more limited as a result of their child's illness. Some parents also described how their other children are affected by their siblings' illness:

> "It has negatively affected the family…we can't play as much as we would like…the children, they can't have pets, they can't be around freshly cut grass or like enjoy the summer months as much as we would like to…it's definitely had a very very very big impact on me and my two sons." – female, age 34

Some parents mentioned how asthma and seasonal changes limit their child's ability to participate in activities:

> "Because of the cold weather…he can't play and he's five so he wants to just jump and he's stir crazy right now, so he can't do what he wants to do and I can't take him outside because [of] the asthma." – female, age 34

Many parents also mentioned that they have a difficult time sleeping because they are checking on or worrying about their children. However, most parents reported that their children are now sleeping well except when they have asthma exacerbations:

> "I've just become very accustomed to like constantly checking up on him. I don't get enough sleep. I mean, it's stressful. I don't get enough sleep because I'm like…I'm very light on my sleep just because…my son has…had like really bad asthma episodes. I mean there were times that my son would be in the hospital like every two or three weeks." – female, age 32

Some parents mentioned how they had been limiting their child's activities and the program helped them discover what their child is capable of:

> "I don't prohibit my child from certain activities. I have learned that you…should not prohibit them. For example if the child wants to swim or something with precautions taken of course, you have to let them be." – female, age 43

Several parents mentioned how their limited resources make it difficult to take care of their children adequately:

> "I don't have enough time for my kids. I have a full time job and I'm a single mom…so I kind of blame myself that I'm not helping my son as much as I should because…of the circumstances." – female, age 32

Communication and desire for outreach

Many parents mentioned the importance of having a contact person to communicate with during the program. Parents mentioned how they appreciated that a CAI staff member called to check in every few months during the program and felt that they could always reach out if they needed to:

> "The asthma initiative just you know really helped us while [my son] was going through you know him being sick with the asthma and at the hospital. They helped us a lot with the last few years, and I know that…I can also reach out if he has…some hard times." – female, age 38

Many parents also expressed desire for more communication and support after the end of the program. One parent said:

> "I wish they would keep in contact more you know like once the program ended or something, just to like call us at least once every 6 months to see what's going on, if we need anything…that would have been nice." – female, age 43

Another parent expressed interest in receiving more electronic forms of communication after the end of the program:

> "I think that there needs to be some type of electronic communication or website available for parents with questions to follow up because it's hard to just retain a number and remember 6 months from now, 'oh, I should call them and try to figure out if there's some help.'" – female, age 43

Help with other problems and access to community resources

When asked about new areas the program could explore, some parents mentioned difficulty with behavioral health and expressed interest in receiving specific behavioral health assistance or referrals from the program:

> "He does have a behavior problem …so he's being referred to places….I think he's also seeing a development specialist at the hospital as well." – female, age 31

Many parents mentioned that their child's asthma had a significant effect on their work. Some parents also mentioned the financial burden of the disease, particularly related to their work:

> "It was really hard to go through all of that. It was hard, it was many months of not working. I lost my job because of that. I had a very stable job...and I mean, I had to leave it because I understand that no boss is going to wait two weeks, a week, for a person who misses so much work….it was an emergency every week…it was very difficult financially because we had to stop working and we had to survive with what we had and we really didn't have that much help." – female, age 44

Another parent suggested that it would be helpful to learn more about policies for parental sick leave:

> "Maybe just helping our parents understand their rights with sick kids or you know, sick children regarding leave or situations like that. Just touching on it." – female, age 43

Of the 22 participants, five had children who had been diagnosed with ADHD and four had children who had been diagnosed with other behavioral, emotional, or mental health problems. Some parents mentioned how it would be helpful to have a program that dealt with ADHD, including education surrounding the impact of medications on children with ADHD:

> "I think I want to understand more about…why my son has ADD, I don't understand [his] behavior sometimes…I would like to get more understanding about that because when my son was diagnosed, when I was told that he had asthma, I didn't know years later I was going to deal with the effects of ADD." – female, age 47

Some parents mentioned that they could use help communicating with their insurance companies, either obtaining insurance or approval for medical devices, such as a nebulizer, which they would also like access to in the community. Some parents mentioned that they would like to enroll their children in other asthma-friendly programs like the free asthma swim program, but had financial limitations:

> "Just some asthma-friendly programs for the kids. You know things like sports or like more swimming classes, especially for us who are low income and can't really afford to…to go out and pay the big bucks for the programs." – female, age 43

Some parents mentioned that they would like more help communicating with and educating their child's school about asthma and asthma medication:

> "So when [the teachers see] certain behaviors come out, I have to tell them it's the medication because that's what I see [at home]…so I have to tell the teachers that my son needs to be given the albuterol and the Flovent." – female, age 47

Discussion

This mixed-methods study provides feedback and suggestions from parents/caregivers and families who have participated in a nurse-supervised CHW asthma home-visiting program in Boston. Quantitative components of the study reveal that supplies, asthma education and help with housing conditions are great strengths of the program. There was a wide range of responses to quantitative questions about housing conditions and pest management with some parents finding the assistance very helpful, while other parents were less positive, presumably because they were still having problems with their housing. Given the CHW's emphasis on remediation of home environmental triggers, both during the home visit and through ongoing case management, this may reflect the poor housing conditions in Boston overall, lack of responsiveness by owners to complaints, even when cited for violations by Inspectional Services, and the length of time it can take to resolve infestations, even when proper techniques are used.

The quantitative ratings also suggest that parents/caregivers would like more help accessing community resources, particularly in relation to behavioral health and social determinants. CAI is currently piloting a social needs screen, which could screen for issues that need to be addressed more consistently beyond those most directly related to asthma control. The social needs assessment asks parents/caregivers about 9 potential needs, including housing, food, medical cost, transportation to medical appointments, utilities, childcare, care of other family members, employment and education.

Qualitative components of the study reveal the importance of communication after the program, suggesting the potential for a quarterly newsletter, website with up-to-date information, or program email, as well as the possibility of communicating with other parents through community-based family workshops or parent support groups (Table 4). Parents would also like more help communicating with schools, finding and maintaining work, obtaining parental sick leave, and more support for the parents’ mental health and their children’s behavioral health needs. Parents also expressed frustration around housing, which is consistent with the lack of healthy, affordable housing in Boston. CAI’s interventions, such as providing supplies and referrals for housing inspections, are often steps in a long process of improving or finding better housing for the family. Qualitative feedback echoed the quantitative findings, reinforcing how supplies and asthma education are big strengths of the program, and reinforcing the importance of using a social needs screen to systematically identify social determinants, particularly with regard to financial limitations.

This study significantly adds to prior literature by assessing families’ experiences with the program and obtaining feedback from parents/caregivers about caring for a child with asthma. There is minimal research available that directly sought feedback from parents and families of children with asthma (6-10). Parental feedback also identified concerns about comorbid ADHD, suggesting the potential for interventions that address both asthma and ADHD in community-based models (17, 18), and the possible role that CHW's might play in addressing behavioral health issues.

A limitation of this study is that, though parents/caregivers were randomized for recruitment, there is self-selection bias in the population of parents who agreed to complete the interviews. Therefore, the responses may not be generalizable to all CAI parents/caregivers or the overall population.

When trying to identify areas that could be addressed during home visits, several parents mentioned ADHD and mental health concerns. Future research should address the relationship between asthma and ADHD, particularly in children from low-income households, and look at the potential of integrating ADHD education and assessment within a nurse-supervised CHW asthma home-visiting model.

Conclusions

Previous research (3-5) has shown that nurse-supervised CHW home-visiting programs are effective in reducing asthma-related ED visits and hospitalizations, missed school days, and missed work days. Quantitative and qualitative elements of this study reveal the potential benefits of using a social needs screen to address more social determinants of health and the need for more communication over time. This could include the option of more extended follow-up for families who choose to continue beyond 12 months, more communication than already exists between program staff and schools, as well as addressing other social determinants and behavioral health concerns for parents/caregivers and families in the community.

With the initiation of the Accountable Care Organization, there is opportunity to expand the scope of the CHW's role while also accounting for capacity based on funding, time constraints, and training and scope of practice, since CHW's are not licensed mental health clinicians. Enhanced services could increase follow-up rates and program efficacy through an increasingly tailored approach toward the needs of the population. These findings are applicable to a variety of home-visiting programs for children and families with often more than one chronic illness. In addition, as "patient-centered care" continues to develop, parent/caregiver and family feedback will become more important in informing these processes. This study provides important feedback from families in order to improve CAI and other chronic illness home-visiting programs.

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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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Appendices

A. Interview Schedule

Quality Improvement Disclosure Statement: This information will be used in summary form without identifying individuals. It may be used in grant reports, presentations or journal papers. We are recording our discussion and will type it up without personal information. Any questions?

<u>Intro/During the Program</u>

1. Tell me about how asthma has affected your family.
    a. Has your child's asthma affected you or your other children?
2. What was your experience with the program?
    a. What parts of the program were most helpful?
    b. Please rate the following parts of the program on a scale of 1-5 with 1 not helpful and 5 very helpful.

Supplies	1 2 3 4 5
Asthma education	1 2 3 4 5
Regular use of asthma medication	1 2 3 4 5
Obtaining asthma medication	1 2 3 4 5
Pest management	1 2 3 4 5
Assistance with housing conditions	1 2 3 4 5
Care in home setting	1 2 3 4 5
Care coordination (*Prompts if needed: help connecting to care, making appointments, following up with urgent care, etc.)*	1 2 3 4 5
Emotional support	1 2 3 4 5
Access to community resources	1 2 3 4 5
Help with other problems such as school, daycare, lack of enough money or food, legal needs, mental health services, child behavior, etc.	1 2 3 4 5

<u>After the Program</u>

1. What has been your experience since the program ended?
    a. Do you feel that your child is doing activities they want to do?
        i. Playing/exercising? Spending time with friends?
    b. How is your child sleeping?
    c. How are you doing? (parent)
        i. Working?
        ii. Sleeping?
2. How can these still be improved? (parent and child)
3. How has your home environment changed due to the program?

4. Does your child have another medical or behavioral problem that would benefit from a program like this?

Future Wishes/Suggestions

1. What changes or improvements would you suggest?
    a. *Prompt if needed: Is there something you wish the home visitor had done differently?*
    b. *Prompt if needed: Is there something you wish you had received more or less of?*
    c. *Prompt if needed: Can you give me one specific change you would make?*
2. Is there something we should offer in terms of resources and referrals in the community?
3. Is there something we should offer in terms of social or emotional support?
    a. Help with your child's emotional or behavioral support?
    b. Help with other family members' social or emotional support?
    c. Help with school issues for your child?
    d. Help with work issues for you?
4. Is there anything else that you wish the program offered to families?
    a. Different kinds of support or services? What else?
    b. Is there anything else you would like to share?

B. Codebook with Definitions

1. Documentation: any documentation that was provided by the community asthma initiative
2. Changes in home environment: any changes to the homes of families during or after their enrollment in the community asthma initiative
3. Child's improvement: any improvements in their child's asthma or quality of life during or after their enrollment in the community asthma initiative
4. Difficulties with asthma: any problems the family or child have had relating to their child's asthma diagnosis
    a. Child's sleep: any disruptions to a child's sleep
    b. Child's stress: any stress the child may experience relating to their asthma diagnosis
    c. Family stress: any stress the family has experienced relating to their child's asthma diagnosis
    d. Limits/concerns about activities: any limitations to a child's activities or concerns about not being able to do activities
    e. No pets: any removal of or inability to have pets as a result of the child's asthma diagnosis
    f. Parent's sleep: any disruptions to a parent's sleep
    g. Weather: any limitations or changes in routine resulting from the weather
5. Financial issues: any financial problems the family or child are experiencing
6. Parts of the program: anything related to a specific part of the program
    a. Access to community resources: any suggestions for or comments about community resources

    b. Assistance with housing conditions: any comments about how the community asthma initiative helped change the conditions of families homes or housing
    c. Asthma education: any suggestions for or comments about the asthma education provided by the community asthma initiative
    d. Care coordination: any suggestions for or comments about the care coordination provided by the community asthma initiative
    e. Care in the home setting: any suggestions for or comments about in-home care provided by the community asthma initiative
    f. Emotional support: any suggestions for or comments about the emotional support provided by the community asthma initiative
    g. Help with other problems: any suggestions for or comments about help with other problems provided by the community asthma initiative
    h. Home visits: any suggestions for or comments about the home visits provided by the community asthma initiative
    i. Obtaining asthma medication: any suggestions for or comments about how the community asthma initiative helped obtain asthma medication
    j. Pest management: any suggestions for or comments about the pest management support provided by the community asthma initiative
    k. Regular use of asthma medication: any suggestions for or comments about how the community asthma initiative helped with regular use of asthma medication
    l. Supplies: any suggestions for or comments about the supplies provided by the community asthma initiative
    m. Visits in hospital: any suggestions for or comments about the visits in the hospital provided by the community asthma initiative
7. Suggestions/Problem areas: Suggestions for program improvement or problem areas that the program did not help enough with
    a. Communication: any suggestions for or comments about communication with the community asthma initiative or communication between the community asthma initiative and the school or community
    b. Health insurance issues: any suggestions for or comments about health insurance issues
    c. Lack of follow up: any suggestions for or comments about issues with follow up during or after enrollment in the community asthma initiative
    d. Moved again: any suggestions for or comments about moving again
    e. None/program was great: any comments about how the program was great or no comments/suggestions
    f. Parent/family support: any suggestions or comments about either a parent support group or a way parents can help each other or other types of family support
    g. Program staff: any suggestions for or comments about the community asthma initiative staff
    h. School issues: any issues related to a child’s school or education
    i. Work issues: any issues with finding or maintaining work, any suggestions for help/improvement with work
8. Time issues: any comments about time as a limitation

Tables with captions

Table 1: Demographics of participants/parents (n=20) and their children (n=22).

Demographic Characteristic	N (%) or Mean (±SD)	
	Participant (Parent)	*Child*
Gender Identity		
Female	19 (95%)	6 (27%)
Male	1 (5%)	16 (73%)
Race/Ethnicity		
Hispanic/Latino	10 (50%)	13 (59%)
Black/African-American	9 (45%)	9 (41%)
White	1 (5%)	0
Average Age	37.1 (7.0) At time of interview	5.7 (3.8) At initial program enrollment
Primary Language		
English	14 (70%)	17 (77%)
Spanish	6 (30%)	5 (23%)
Parent Education		
8th grade or less	1 (5%)	
Some high school	6 (27%)	
High school graduate/GED	4 (18%)	
Some college/vocational or technical school	9 (41%)	
Graduated from college/graduate school	2 (9%)	
Family Income (Baseline)		
Less than $25,000	19 (86%)	
$25,000-$50,000	3 (14%)	

Table 2: Demographics of children whose parents/guardians were interviewed (n=22) or not interviewed (e.g. declined/unreachable) (n=78).

Child's Demographic Characteristic	**N (%) or Mean (±SD)**		**p-value**
	Interviewed	*Not Interviewed*	
Gender Identity			0.11
Female	6 (27.3%)	36 (46.2%)	
Male	16 (72.7%)	42 (53.8%)	
Race/Ethnicity			0.27
Hispanic/Latino	13 (59.1%)	32 (41%)	
Black/African-American	9 (40.9%)	37 (47.4%)	
White	0	3 (3.8%)	
Other/Declined	0	6 (7.6%)	
Average Age	5.7 (3.8)	7.2 (3.8)	0.14
Primary Language			0.59
English	17 (77.3%)	52 (66.7%)	
Spanish	5 (22.7%)	25 (32.1%)	
Other	0	1 (1.3%)	
Parent Education			0.19
8th grade or less	1 (4.5%)	3 (3.8%)	
Some high school	6 (27.3%)	13 (16.7%)	
High school graduate/GED	4 (18.2%)	17 (21.8%)	
Some college/vocational or technical school	9 (40.9%)	21 (26.9%)	
Graduated from college/graduate school	2 (9.1%)	6 (7.7%)	
Other/Declined	0	18 (23.1%)	
Family Income (Baseline)			0.50
Less than $25,000	19 (86.4%)	61 (78.2%)	
$25,000-$50,000	3 (13.6%)	13 (16.7%)	
Declined	0	4 (5.1%)	
Asthma Severity Score			0.49
Intermittent	0	2 (2.6%)	
Mild Persistent	4 (18.2%)	25 (32%)	
Moderate Persistent	11 (50.0%)	27 (34.6%)	
Severe Persistent	1 (4.5%)	7 (9%)	
Unknown	6 (27.3%)	17 (21.8%)	

*percentages may not total 100 due to rounding

Table 3: Average ratings by program part and areas of need on a 1 (not helpful) to 5 (very helpful) scale. Means and standard deviations were calculated excluding missing values.

Part of core program	N	Mean rating (±SD)
Supplies	20	4.65 (0.99)
Asthma education	20	4.75 (0.55)
Regular use of asthma medication	20	4.55 (1.00)
Obtaining asthma medication	18	4.61 (0.98)
Pest management	19	3.79 (1.69)
Assistance with housing conditions	17	3.94 (1.56)
Care in home setting	19	4.37 (1.26)
Care coordination ***(Prompts if needed: help connecting to care, making appointments, following up with urgent care, etc.)***	19	4.47 (0.96)
Emotional support	20	4.30 (1.08)
Further social determinants to address		
Access to community resources	20	3.70 (1.30)
Help with other problems such as school, daycare, lack of enough money or food, legal needs, mental health services, child behavior, etc.	15	3.05 (1.78)

Table 4: Participants suggestions for program improvement.

Thematic Code	Representative Quotations
Communication/Desire for more outreach	"I wish they would keep in contact more you know like once the program ended or something, just to like call us at least once every 6 months to see what's going on, if we need anything…that would have been nice." – female, age 43 "I really like to get the news magazines and emails from you guys, but it doesn't seem like there's someone to reach out to after the program, a contact person." – female, age 28
Family and Parental Stress/Limitations	"[Asthma] has negatively affected the family. We can't play as much as we would like, the children, they can't have pets, they can't be around freshly cut grass or like enjoy the summer months as much as we would like to. It's definitely had a very, very, very big impact on me and my two sons." – female, age 34
Help with other problems/Access to Community Resources	"It was really hard to go through all of that. It was hard, it was many months of not working. I lost my job because of that. I had a very stable job. I had a stable job and I mean, I had to leave it because I understand that no boss is going to wait two weeks, a week, for a person who misses so much work….it was an emergency every week…it was very difficult financially because we had to stop working and we had to survive with what we had and we really didn't have that much help." – female, age 44
Emotional Support	"I think the most useful part was the attention I was given. Like they made me feel like I wasn't alone, that there were people who were interested in my case and that…that there was hope for us with a program like this that could provide the resources to cope with our problem." – female, age 44
Asthma Education	"It opened my eyes a lot, gave me a lot of education that even as a nurse that I didn't even realize. Though it's different when your child is the patient…it just helps having the

	individual person, that one to one, that just gave you all their time. It was a good program." – female, age 31
Praise for the Program	"My personal experience was awesome. I had an awesome woman who came to my home. I mean, I loved it. I really enjoyed the conversations and us talking and making sure that I was up to date on everything and how to make sure I had his medications and everything on point." – female, age 36

Figures

Figure 1

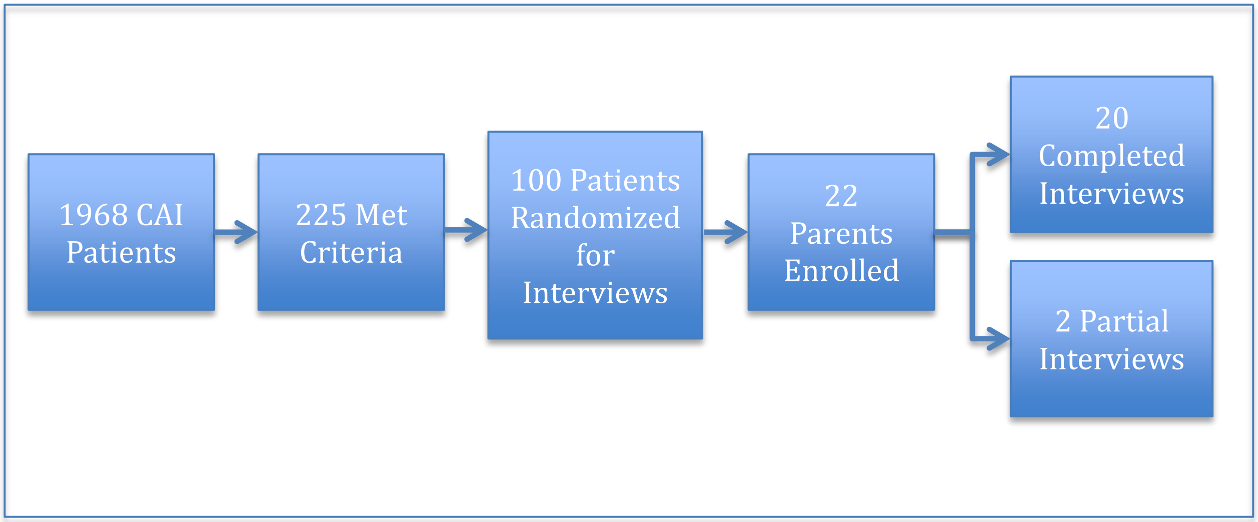

Figure 2

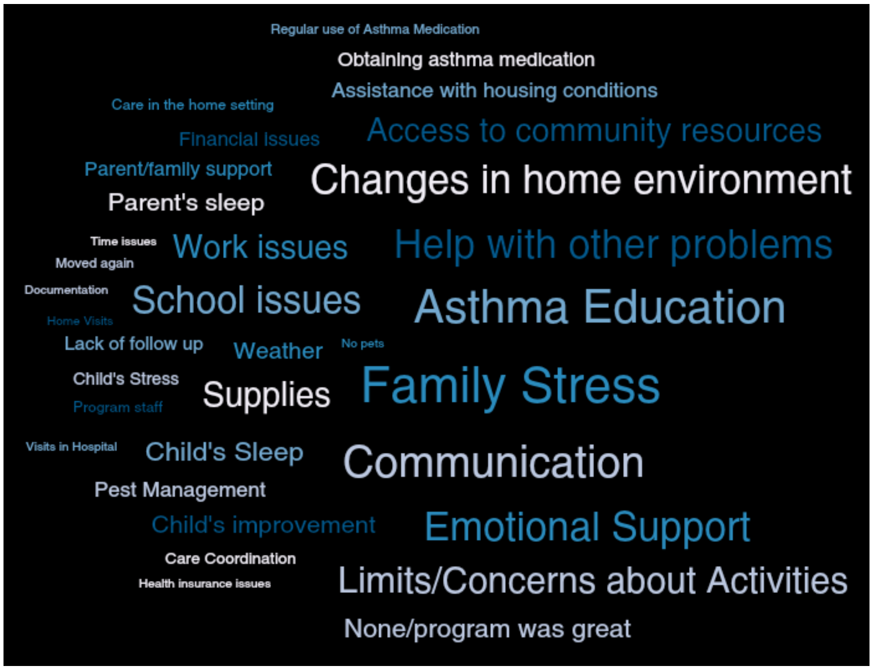

Figure Captions

Figure 1: Selecting a representative sample of parents for quality improvement interviews from the main Community Asthma Initiative (CAI) population.

Figure 2: Code word cloud with size in proportion to frequency of codes in interviews.