

Pediatric Asthma Hospitalization in San Francisco: Causal Factors Perceived by Medical Providers and Family Caregivers and Proposed Interventions

Two Human Subjects Research Projects of the
San Francisco Asthma Task Force and Clinical Partners

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Acknowledgements

Study I: California Pacific Medical Center (CPMC), California Campus and St. Luke's Campus Pediatric Asthma Hospitalizations (January 1, 2005 through July 31, 2007)

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Fiscal Agent: Asthma Resource Center of San Francisco, Inc.

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Study II: San Francisco General Hospital (SFGH) Pediatric Asthma Hospitalizations (January 1, 2007 through December 31, 2008)

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Fiscal Agent: Asthma Resource Center of San Francisco, Inc.

Title of Project as submitted to UCSF Committee on Human Research: Identifying Causal Factors for Pediatric Asthma Hospitalizations at San Francisco General Hospital to Propose Appropriate Interventions

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UCSF Committee On Human Research (CHR) application: Literature review and goals, Peter Capucilli and Lucile Baul

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Contents



- 2** Genesis of the San Francisco Asthma Task Force Human Subjects Research
- 4** Background and Significance
- 7** **Study I: California Pacific Medical Center (CPMC), California Campus and St. Luke's Campus Pediatric Asthma Hospitalizations (January 1, 2005 through July 31, 2007)**
- 7** Study I Project Design
- 9** Study I Project Methods
- 10** Study I Patient Family Survey Responses
- 12** Study I Clinician Focus Group Findings
- 13** Study I Intervention Planning
- 14** **Study II: San Francisco General Hospital (SFGH) Pediatric Asthma Hospitalizations (January 1, 2007 through December 31, 2008)**
- 14** Study II Project Design
- 15** Study II Project Methods
- 15** Study II Patient Family Survey Responses
- 18** Study II Clinician Focus Group Findings
- 19** **Study I and Study II: Discussion of Patient Family Survey Responses**
- 26** **Study I and Study II: Discussion of Clinician Focus Group Findings**
- 27** Themes: A. Patient Barriers and Challenges
- 35** Themes: B. Provider Barriers and Challenges
- 43** **Study I and Study II: Clinical Interventions Related to Research Findings**
- 46** References

Genesis of the San Francisco Asthma Task Force Human Subjects Research



Community activists from the Bayview Hunters Point district and allies first identified asthma as a key issue for school children in Bayview Hunters Point and later, for all age groups citywide. They advocated for the creation of a citywide task force to address the epidemic of asthma through primary prevention and environmental strategies, with an emphasis on reducing asthma disparities disproportionately affecting lower income communities. As a result, the Board of Supervisors created the San Francisco Asthma Task Force (ATF or Task Force) in 2001. The Task Force issued its *Strategic Plan* in May 2003, shortly after the asthma deaths of two children and one adolescent in San Francisco. One of the bereaved mothers sought out the Task Force so that she could record a message to other parents letting them know something that she had not understood at the time of her child's death, is that children can die from asthma and also that asthma can be controlled. The video produced with support from Kaiser Permanente San Francisco can be accessed from the Task Force website, <http://www.sfgov.org/asthma>.

The Task Force next focused on the prevention of pediatric asthma hospitalizations, applying with its fiscal sponsor, the Asthma Resource Center of San Francisco, Inc. (ARC, Inc.) for a 2006 Community Health Award granted by the California Pacific Medical Center (CPMC) to research this issue. Project rationale included the finding that no other resource was specifically analyzing the causal factors of San Francisco asthma hospitalizations; and that such analysis can include existing efforts to improve asthma management and whether they adequately address causal factors. For this research project, CPMC data evaluated included those pediatric hospital admissions for asthma from both the California Campus and the St. Luke's Campus of CPMC.

In the CPMC online *Pediatric News*, asthma was mentioned in ten of 12 consecutive issues with a "Who Have We Been Admitting?" heading, from 12/04 to 12/05. CPMC California Campus winter 2005 hospital admissions for asthma improved from prior winters, credited to Sutter Health's asthma clinical initiative with outpatients as well as created greater attention to providing asthma action plans and inhaled corticosteroids to discharged patients. CPMC California Campus estimated pediatric asthma hospitalizations were 20-40/quarter.

St. Luke's Campus provided spirometry and education for admitted patients and those in the ER with asthma flares. In 2004-2005, St. Luke's asthma educator served approximately 140 children hospitalized for asthma, providing bedside education and an educational asthma kit.

The Asthma Task Force's stated research goal for Study I was to obtain description of causal factors for pediatric asthma hospital admissions primarily at the CPMC California Campus and St. Luke's Campus via focus groups for clinicians and self-administered questionnaire to families of patients hospitalized due to asthma over a two-and-half-year period (1-1-05 to 7-31-07), i.e., having some indication of Asthma DX as a diagnosis name and code, although something else may have been listed as the principal diagnosis. Specific outcome objectives of this project were to:

1. Identify perceived causal factors for pediatric asthma hospitalizations in San Francisco.
2. Propose appropriate interventions.

3. Develop collaboration with the African American Community Ambassadors/ Hospital Navigators Program to pilot proposed resources and interventions.

Following the perceived causal analysis of pediatric asthma hospitalizations at both CPMC California Campus and St. Luke's Campus, Asthma Task Force member Nanette Madden, MS, CNS, PNP, Associate Clinical Professor UCSF School of Nursing, Clinical Director, Pediatric Asthma Clinic, San Francisco General Hospital, obtained UCSF Committee On Human Research (CHR) approval to repeat this research design with SFGH pediatric medical providers and two years of SFGH pediatric asthma hospitalization data (from January 1, 2007 through December 31, 2008).

The UCSF CHR application synopsis states that Study II focused on the caregivers of children and adolescents, age birth to 18 years of age, who were hospitalized for asthma during a two-year period at San Francisco General Hospital. The study collected and examined the perceptions of the child's family caregiver regarding the factors that led up to the child's hospitalization. The study also collected information from primary care providers at San Francisco General Hospital regarding their opinion of the causes of pediatric hospitalizations for asthma in general. The purpose of obtaining this data was to help design strategies to decrease pediatric hospitalization rates.

Study II's specific aim was to obtain and analyze the descriptions that parents/guardians and primary care providers in San Francisco provided regarding their perceptions of the causal factors for the onset both of asthma episodes and of the deterioration leading to hospitalization. By obtaining and analyzing these descriptions and by sharing findings with the medical community, insight was gained that supports the following:

1. Reduced health disparities in adverse asthma outcomes in San Francisco.
2. Interventions that address San Francisco-specific causal factors.
3. The provision of specific knowledge for medical providers of appropriate risk factors associated with pediatric asthma.
4. Strategies to improve the quality of care and quality of life for children with asthma and their families.
5. Decreased pediatric hospitalization rates by better understanding perceived reasons for the hospitalizations and by providing both family caregivers and clinicians with information that will help them design strategies to prevent hospitalizations.

Background and Significance



Asthma is a chronic respiratory disease characterized by recurrent episodes of inflammation and narrowing of the small airways, leading to symptoms such as wheezing, coughing, chest pain, and shortness of breath (National Heart Lung and Blood Institute [NHLBI], 2012). The severity of these symptoms range from mild to life-threatening and are commonly exacerbated by triggers such as, but not limited to, allergens (e.g., pet dander, cockroaches, pollen), exercise, infection, changes in weather, and exposure to irritants (Milet et al., 2007). While the exact causes of the onset of asthma are unknown, people with a family history of asthma are more prone to the condition and research suggests that exposure to tobacco smoke, infection, and allergens also increase the likelihood of developing asthma (NHLBI, 2012).

The California Department of Public Health issued *“Asthma in California: A Surveillance Report”* in May 2013. Key findings excerpted from that report include:

Prevalence

- In 2010, 13.1% of adults and 12.5% of children had been diagnosed with asthma at some point in their lives (lifetime asthma); 7.9% of adults and 7.4% of children had current asthma.
- Each year, there are an estimated 189,700 new cases of asthma in California – approximately 93,150 among adults and 96,550 among children.
- Among males with asthma, a higher percentage had their asthma start as a child (69%) than as an adult (31%). Among females with asthma, roughly the same percentage had their asthma start as a child (48%) or as an adult (52%).

Morbidity and Control

- The majority of adults and children with current asthma (65.9% and 53.7% respectively) had asthma symptoms in the past month.
- Approximately 129,000 children with current asthma (52.3%) missed school or day care because of their asthma at some point in the past year. This translates to an estimated 1.2 million days of school/day care missed per year.
- While most adults and children with current asthma are classified as having well controlled asthma, over one in five are considered to have very poorly controlled asthma.
- Compared to those with well controlled asthma, people with poorly controlled asthma are more likely to miss work or school, have an ED visit for asthma, or be hospitalized for asthma.

Disparities

- Blacks have the most striking disparity in the burden of asthma. Compared to Whites, Blacks have 40% higher asthma prevalence, four times higher asthma ED visit and hospitalization rates, and two times higher asthma death rates.
- Hispanics have comparatively low asthma prevalence overall, but asthma hospitalization and ED visit rates are higher in Hispanics than Whites, especially among children.
- Pacific Islanders and Filipinos are two subgroups with a high asthma burden; both have high lifetime asthma prevalence, asthma mortality rates, and Medi-Cal asthma hospitalization rates.
- The rate of asthma hospitalizations and ED visits is four times higher for people living in areas where the median household income is \$20,000 or less compared to those living in areas where the median household income is more than \$100,000.
- Asthma affects people of all ages, but asthma prevalence, hospitalization rates, and ED visit rates are higher for children than adults.
- People born in the U.S. are more likely to have asthma than people born outside of the U.S. The disparity is largest for Hispanics and Asians, who are two to three times more likely to have asthma if they were born in the U.S.

Risk Factors

- Almost 12% of adults and teens with current asthma are smokers.
- About 10% of adults with current asthma and 5% of children with current asthma are exposed to secondhand smoke in the home.
- On average, people with asthma are exposed to 2-3 asthma triggers in the home (e.g., mold, cockroaches, rodents, pets, carpeting, wood burning or gas appliances, and tobacco smoke).
- As in the general California population, about 40% of people with asthma are renters, which can impact a resident's ability to reduce exposure to asthma triggers in the home.
- Outdoor air pollutants are important asthma triggers; their levels vary widely across the state.

Literature Review Conducted for UCSF CHR

In the research literature, multiple approaches have been employed to assess the causal factors related to hospitalization for asthma among children (Finkelstein, et.al, 2000, Warman, et. al, 1999, Haby and Powell, 2002, Flores, et.al, 2003, Flores, et. al, 2005, Mansour, et. al, 2000, Wright, et. al, 2004). The subjective beliefs and experiences of both caregivers and clinicians in this area are of particular interest and may help identify some of the barriers to effective asthma management in children (Camargo, et. al, 2007, Miller, et.al, 2007, Reindal, 2006, Flores et. al, 2003, Flores, et. al, 2005, Mansour, et. al, 2000).

The assessment of clinicians has uncovered a number of clinician beliefs regarding barriers to effective asthma care. Flores and colleagues (2003, 2005) note that both primary care providers and inpatient attending physicians are more likely to believe that hospitalization is preventable than parents and caregivers. These physician groups identify delay in obtaining care, lack of follow-up care, and lack of compliance with prescribed medications as contributors to

admissions. Other behaviors, such as failure to immunize and failure to monitor peak flows are also cited as factors contributing to admission by primary care physicians, and inpatient physicians cite parent education and insufficient time to care for children as contributors. Both physician groups believe that lack of an identified primary care provider and medical home, pharmacy issues, and their own lack of time to manage complicated cases increase morbidity and risk (Flores, et. al, 2003, Flores, et. al, 2005).

In contrast to physician beliefs, several different areas have been identified in the parent/caregiver arena as contributors to pediatric asthma admissions, including beliefs about environmental controls, medications, and overall trust of the medical system. Flores and colleagues (2003, 2005) report that, while some parents agree that delay to care is a contributor to admissions, they are much less likely to believe that their child's hospitalization is preventable. Parents identify barriers to care related to the child's environment – inability to avoid triggers, difficulties convincing landlords to eliminate infestations, remove carpet, improve heat, decrease mold, etc. (Cabana et al., 2004, Aligne et al, 2000, Wright et al., 2004, Wever-Hess, 2001, Flores, et. al, 2003, Flores, et. al, 2005). In terms of medication use, parents also have beliefs regarding medications that differ from those of physicians. Mansour and colleagues (2000) note that health beliefs, such as concerns about the use, safety, and long-term complications of controller medications influence caretaker behavior, and similarly, Bender and Bender (2005) report parental concerns over drug safety, drug dependence, and decreased drug effectiveness. Additionally, some parents believe that their child's asthma is not serious enough to warrant daily medication use.

Mansour and colleagues (2000) find that some parent/caregivers would prefer physicians to use more holistic approaches to treatment and prevention, and, in addition, they report that the instructions they do receive are not specific enough to follow appropriately. Other parent/caregivers in this study (Mansour, et. al, 2000) want to have more control over their child's treatment including medication use. Finally, Frederickson and associates (2004) report that mothers of children receiving Medicaid are very critical of the health care system and believe that the lack of preventive care services and case management, encouragement to use the emergency department, lack of after hours care and convenient acute care appointments put their asthmatic children at risk for increased morbidity.

Overall, it is clear that there are both conflicting and similar beliefs held by both clinicians and parents as to the key factors contributing to hospitalization for childhood asthma. (Flores, et. al, 2003, Finkelstein, et. al, 2000, Wright, et. al, 2004, Mansour, et. al, 2000). It is likely that many of the specific factors previously identified are unique to particular communities – for example, issues related to resources are more likely to be factors in those with sub-optimal health insurance and issues related to mold are more likely to exist in areas of high humidity.

No systematic review of these factors had been conducted in San Francisco. The intention of the Asthma Task Force's human subjects research was to embark on an assessment of both clinicians and family caregivers in our community with the goal of identifying areas of intervention that may help contribute to a decrease in pediatric asthma hospitalizations.

Study I: Sutter Health, California Pacific Medical Center (CPMC), California Campus and St. Luke's Campus Pediatric Asthma Hospitalizations (January 1, 2005 through July 31, 2007)



Study I Project Design

As a human research subjects proposal, ATF had to first obtain California Pacific Medical Center (CPMC) Institutional Review Board (IRB) approval for the project, titled "Identifying Causal Factors for Pediatric Asthma Hospitalizations in San Francisco to Propose Appropriate Interventions", with the support of Principal Investigator Dr. David Tejada, MD from the CPMC California Campus Family Health Center and Pediatrics Department.

A. Patient Family Surveys

Additionally, the study consisted of a self-administered anonymous questionnaire which was mailed to the family members of pediatric patients with asthma admissions occurring from January 1, 2005 through July 31, 2007 at both the CPMC California and St. Luke's Campuses. Questionnaires were translated into English, Spanish, and Chinese and distributed according to the primary language on record for that family. The questionnaire focus was to identify perceived causal factors for asthma hospitalizations by parents and guardians. The questionnaire included certain non-identifiable demographic information. Surveys and stamped return envelopes were coded to retain anonymity and to identify which non-responding families should receive a repeat mailing. The IRB at CPMC would not allow ARC, Inc and ATF to provide incentives for survey participation.

Other IRB criteria included:

- 1. Methods of Data Analysis:** Analysis included qualitative descriptions by theme and limited statistical analysis. Themes included the perceived causal factors of hospitalizations, the cultural and linguistic appropriateness of current asthma care, contribution of psychosocial stressors such as domestic and community violence as barriers to effective asthma management, and transportation barriers to patient care.
- 2. Subject Selection:** Inclusion was intended to capture all parents and guardians of children and youth ages 0-17 years old at the time of admission to the hospital for the primary and/or secondary diagnosis of asthma, and admissions from January 1, 2005 through July 31, 2007. Exclusion occurred if a potential questionnaire participant could not read and respond to an English, Chinese or Spanish written survey well enough to understand the questions, as use of oral interpretation was not part of the protocol.
- 3. Subject Recruitment:** Recruitment involved sorting of hospital admissions data at CPMC California Campus and St. Luke's Campus, with subsequent contacting by mail of the families of children and youth 0-17 years old hospitalized with the primary diagnosis of asthma, and admissions occurring from January 1, 2005 through July 31, 2007.
- 4. Consent Process and Documentation:** Consent and HIPPA waiver forms were utilized. The questionnaires and return envelopes were coded to remain completely anonymous and did not contain any identifying material. The study included non-English speakers and the cover letter and questionnaire were translated into Spanish and Chinese.

5. Risks/Discomforts: Participants may have experienced some discomfort from answering questions concerning their child's hospitalization. The issue of one's child being hospitalized can cause shame for parents and guardians, which may have been re-stimulated by the questions posed in the questionnaire. Because the questionnaire was voluntary and confidential, participants were given the option not to participate. In addition, the researchers were available to answer questions of the participants and were trained on recognizing potential issues involved in participation in the survey.

It was hypothesized that child caregivers (parents or guardians) would identify social-economic and environmental problems such as poor housing conditions, competing needs and lack of transportation as contributors to their child's hospitalization. The family survey questions were designed with an emphasis on eliciting parent and guardian recall about known medical standard of care and environmental risk factors related to asthma hospitalization, such as:

1. What is their understanding of the conditions that led to the hospitalization?
2. What asthma management resources did they receive prior to or subsequent to the hospitalization, and what did they find most useful?
3. What type of asthma medicines were taken by their child at the time of the hospitalization?
4. What advice would they give other parents to avoid asthma hospitalization?
5. What other things in the child's home/school/community may have contributed to their hospitalization?

B. Clinician Focus Groups

The study consisted of four focus group discussions to include primary care clinicians who have in the past admitted pediatric patients to CPMC California Campus and St. Luke's Campus hospitals for asthma. Providers were invited to a one-time focus group with lunch provided, and all participants received \$100 gift cards to Nordstrom.

Through the primary care provider focus groups, perceived causal factors for pediatric asthma hospitalizations were identified by use of the following research questions:

1. Do you believe that it would ever be possible to prevent asthma hospitalizations?
2. If yes, how can we prevent asthma hospitalizations? What are the steps involved?
3. What are the barriers and challenges to preventing hospitalizations?
4. In a perfect world that you had control over, how would you begin to prevent children's hospitalizations for asthma?
5. Could there be other non-clinical factors serving as barriers to the prevention of hospitalizations?
6. Are there risk factors involved that contribute to in children being hospitalized for asthma?
7. Are there ways that the Asthma Task Force can create or advocate for interventions or changes that may lead to a decrease in hospitalizations of children for asthma?

The focus groups took place for one and a half hours each and were audio-taped. All focus group discussion followed a defined focus group protocol and remained confidential.

Study I Project Methods

A. Patient Family Surveys

Due to the time lapse between hospitalizations occurring from January 1, 2005 through July 31, 2007 and IRB approval in July 2007, some families received the surveys up to 2.5 years following their child's hospitalization. In the mailing, they received a cover letter stating that "the San Francisco Asthma Task Force and California Pacific Medical Center are working together to improve the quality of life for children with asthma and their families, and looking to hear from families whose child has been hospitalized for asthma so that their experience will teach the research partners how to help other families." Parents and guardians were invited to answer the enclosed coded questionnaire and told that everything reported on the questionnaire would remain confidential; a coded, pre-addressed and stamped return envelope was provided. Families were thanked for considering participation in this project, but the IRB at CPMC would not allow ARC, Inc and ATF to provide incentives for survey participation.

Written surveys in English, Spanish or Chinese were mailed to each family, according to the family's primary language on record. Surveys were mailed four times total, each time to those who had not responded to earlier mailings, to encourage a greater response rate. As relevant, all survey questions provided for multiple answer categories to be selected per question and additional space for write-in responses that might differ or add to the designated response categories. All data was considered subjective and the intent was to uncover the perceptions of family caregiver(s) answering the survey.

B. Clinician Focus Groups

Focus groups were designed as an opportunity for clinicians to anonymously contribute their experience and thoughts regarding factors that may contribute to children being hospitalized for asthma, and providers received two incentives for their participation, a lunch and a \$100 gift card to Nordstrom.

All focus group proceedings were audio-tape recorded and data from the focus group tapes was compiled and transcribed using standard word processing software. While this process was time and labor intensive, it ensured the content and meaning within the gathered information would be captured with the greatest accuracy possible. In addition to the focus group tapes, field notes and notes from debriefing discussions with facilitators were transcribed.

The audio-taped discussion was later coded for themes by ATF's qualitative evaluation consultant, Vickie Krenz, PhD, an academic researcher from Cal State Fresno, by importing compiled transcriptions into text analysis software (Envivo Nudist). With the transcriptions, a cross-case analysis was performed to group together answers for common questions to identify central issues and/or themes. Utilizing the "issues-based" framework, case studies qualitative analysis was conducted in which a comprehensive classification system of identified themes was developed consisting of several general categories and subcategories and corresponding coding assigned; reference: Patton, M.Q. (2002). *Qualitative Research and Evaluation Methods*. (3rd ed.) Thousand Oaks, Calif.: Sage.

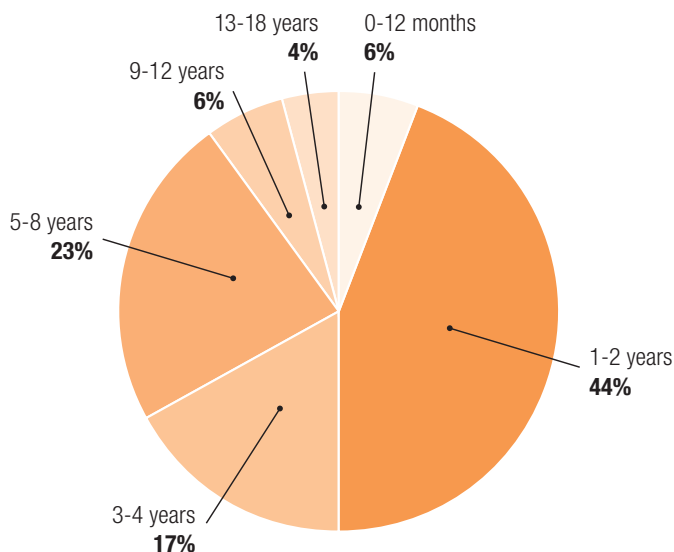
Analysis of the focus group qualitative data included qualitative descriptions by theme. The themes included the perceived causal factors of hospitalizations, barriers and challenges to preventing hospitalizations, the cultural and linguistic appropriateness of current asthma care, the contribution of psychosocial stressors such as domestic and community violence as barriers to effective asthma management, and interventions or changes to decrease hospitalizations of children for asthma.

Study I Patient Family Survey Responses

Respondents:

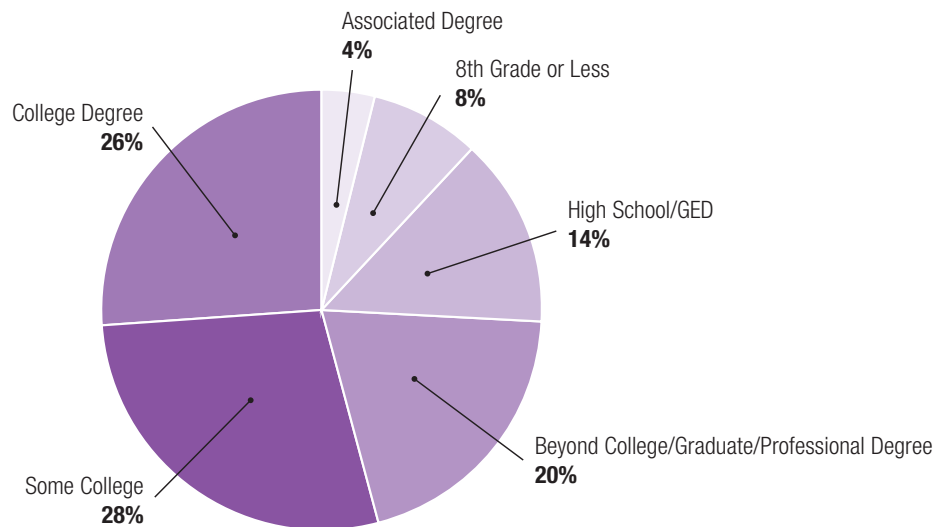
Surveys were mailed to 255 families of hospitalized patients, 129 who were San Francisco residents and 126 who were not San Francisco residents. Fifty recipients completed and returned the surveys (20% response), with 33 (26%) returned from San Francisco residents vs. 17 (13%) from non-SF residents. Surveys were completed and returned as follows: 14 surveys completed on 1st mailing, 16 completed on 2nd mailing, 7 completed on 3rd mailing, and 13 completed on 4th mailing. 80% of the respondents identified themselves as the mothers of the patient.

Age of your child at the time of hospitalization for asthma. N = 48



The top two race/ethnicities of people completing and returning surveys were: Asian (26%) and Caucasian (19%). The primary language spoken at home included 60% English, 24% Cantonese and 10% Spanish. Respondent level of education is shown on the figure below, indicating that the majority of respondents had an educational level that included college attendance or a college or graduate level degree.

What is your highest level of education you have completed? N = 50



Key Findings:

- The greatest proportion of respondents (44%) stated their child was between 1-2 years of age at the time of their hospitalization.
- Cold, virus or flu was identified as the top reason for hospitalization.
- Increased coughing and wheezing as well as cold, virus and flu were identified as top two reasons leading up to hospitalization.
- 72% of the respondents said they and their doctors understood the reason for hospitalization.
- 68% of patients were taking medication at the time of hospitalization; of those, 31% were using both an asthma controller and rescue medicine, 32% were using an asthma controller medicine alone, and 23% were using a rescue medicine alone.
- 66% of patients have seen an asthma specialist, primarily a pulmonologist.

Asthma Resources Received:

- Approximately 70% of the parents stated they were not referred to resources on how to manage their child's asthma prior to the hospitalization. Post hospitalization, 74% were referred to resources on how to manage asthma.
- When asked about resources that they found to be helpful, responses as reported by 50 respondents indicated that these resources were the most helpful to them: nebulizer (38 times), books/written materials (15 times), mattress/pillow allergen covers (12 times), asthma class or consultation (11 times), spacer (8 times), peak flow meter (8 times), video and other (7 times), and extra medication for school (6 times).
- Family members were also asked to indicate what type of resources would have been helpful to receive. Education about asthma (22), allergy control products (19), permission to leave job for child's medical appointments (9), help with paying for medications (9), help with transportation (7), and more time for questions (5).

Peer-to-Peer Advice:

The survey established how the hospitalization experienced by these families might shape how they would advise other parents to potentially avoid their child being hospitalized for asthma. Respondents selected all answer categories as being important: Ask more questions of medical provider (20); Be more observant of changes in your child's behavior or asthma symptoms (40); Follow medical treatment plan and speak to doctor or nurse if it isn't working (33); Let your child's school/child care know about their asthma (25).

Social Determinants and Environmental Risk Factors:

In seeking to find out social determinants and environmental risk factors affecting asthma control, parents and guardians were asked "Do you think that there are other things in your child's home/school/community which may have contributed to their hospitalization?" Responses indicated with the most frequency included: mold/dampness (11), unhealthy school/child care environment (7), household cleaning products (7), other (6), closeness to freeway or heavy traffic (5), diesel trucks nearby (5) and gas stove in home (5).

Study I Clinician Focus Group Findings

Participants:

Four focus groups were held in April 2008, and participants included a total of 22 pediatric primary care medical providers with admitting privileges at the two CPMC Campuses. The participants were mostly primary care providers, including physicians, physician assistant, and nurse practitioners, as well as a pulmonary specialist. They work in a diverse set of neighborhoods and serve patients that are diverse both ethnically and economically; these include: Bay View Hunters Point, a low income area, historically African American, but increasingly an Asian and Latino neighborhood, the Sunset District of San Francisco, a middle income community, the Mission District, a primarily low income Latino and Filipino neighborhood, the upper middle class Laurel Heights neighborhood, low income and primarily Chinese monolingual and limited English-proficient Chinatown, and nearby middle income Daly City. Some clinicians are in private practices, some in hospital-based outpatient clinics and two worked as faculty or preceptors for nursing and nurse practitioner students. Some of the providers only work with patients who have commercial insurance, while many work primarily with patients utilizing public insurance, such as patients utilizing Medi-Cal (Medicaid) and the Healthy Family Program (CHIP).

Key Findings:

As described above, themes were generated from the four focus groups to address the issue of hospitalizations of children for asthma in San Francisco. The themes included the perceived causal factors of hospitalizations, barriers and challenges to preventing hospitalizations, the cultural and linguistic appropriateness of current asthma care, the contribution of psychosocial stressors such as domestic and community violence as barriers to effective asthma management, and interventions or changes to decrease hospitalizations of children for asthma.

Providers identified a different set of causal factors than parents and guardians. These included caregiver lack of understanding of the pathophysiology of asthma, lack of awareness of triggers, lack of understanding of the mechanics of medical devices as well as general non-compliance with controller medications, and lack of access to urgent care on weekends and evenings.

- Providers found it very difficult to manage asthma, and felt that time restraints made it difficult to integrate education into the office setting. There was frustration about the difficulty in providing education that appeared not to be retained, having to repeat the same messages over and over again.
- Providers attributed lack of retention of self-management education to a variety of factors, such as the need to exchange information among multiple family caregivers, denial of asthma as a chronic disease, family issues, and investment of time, competing day-to-day demands, and concerns about medications and money for insurance co-payments represent some of the barriers identified.
- Also caring for teens provided an additional set of challenges including medication non-compliance, denial of chronic nature of asthma, and parental manipulation.
- There were also cultural and linguistic issues including health beliefs about illness, treatment strategies and medication.
- Increased referral to allergists and pulmonologists was seen as a way to decrease hospitalization, as was consistent follow-up.

- There was provider agreement that some children and youth will continue to be hospitalized for asthma over time even in the context of the best care model.
- It was pointed out that there are no easy solutions because asthma is a complex chronic illness to manage.

Study I Intervention Planning

A planned outcome of the study was to help develop an educational intervention to be used in the primary care setting to help prevent asthma exacerbations and hospitalizations, and as feasible, to work in collaboration with the African American Health Initiative Navigator Program. A conference call was held on July 20, 2009 with research partners, including medical providers from CPMC California and St. Luke's Campuses, representatives of the Asthma Task Force and fiscal agent Asthma Resource Center of San Francisco, Inc., and the project's academic evaluation consultant, to develop such an educational intervention.

Possible intervention strategies that were discussed by the group and referred for further exploration included:

- An asthma bracelet for patients
- An educational goody basket for patient families
- Use of chronic care model and spirometry in the primary care clinical setting
- An AmeriCorps team that would bring education to the practice site

Results: In subsequent years, through grants awarded by Kaiser Permanente San Francisco Community Benefits from 2007-2012, the Task Force and Asthma Resource Center Inc. promoted interventions that matched some of those named above:

- Primary care use of the chronic care model for systems change that supports patient self-management of asthma;
- Primary care use of office-based spirometry;
- Use of AmeriCorps (Community HealthCorps) members as asthma educators at several community safety net clinics;
- Use of AmeriCorps (Community Health Corps) member as asthma and obesity prevention health educator at a San Francisco Department of Public Health (SFDPH) Youth Clinic located at a San Francisco Unified School District (SFUSD) high school.

Study II: San Francisco General Hospital (SFGH) Pediatric Asthma Hospitalizations (January 1, 2007 through December 31, 2008)



Study II Project Design

As a human research subjects proposal, ATF and Co-Principal Investigator, Nanette Madden, PNP, Clinical Director of the San Francisco General Hospital Children's Health Center Pediatric Asthma Clinic had to first obtain San Francisco General Hospital Institutional Review Board (IRB) approval as well as University of California San Francisco (UCSF) Committee on Human Subjects Research (CHR) approval for the project, titled "Identifying Causal Factors for Pediatric Asthma Hospitalizations in San Francisco to Propose Appropriate Interventions", with the help of students Peter Capucilli and Lucile Baul.

The study included parents or guardians of children who met the following criteria:

- a. Diagnosis of asthma based on a clinical assessment of the attending pediatrician while hospitalized
- b. Age birth to 18 years of age
- c. Hospitalized for asthma as a primary or secondary diagnosis from January 1, 2007 through December 31, 2008

The parents or guardians who met the following criteria:

- a. Present as caregiver at time of hospitalization
- b. Able to read English, Spanish, or Cantonese

The study included primary care providers who met the following criteria:

- a. Those who have worked full or part-time in the Pediatric Clinic at San Francisco General Hospital for at least 12 months
- b. Those willing to sign a consent form to participate in the discussion group

A. Patient Family Surveys

The same self-administered anonymous questionnaire (available in English, Spanish and Chinese) that was mailed to the family members of pediatric patients in Study I was used for this Study. The study subject population was defined as 104 children 0-18 years old with primary and/or secondary diagnosis of asthma admitted to San Francisco General Hospital over a 24 month period, from January 1, 2007 through December 31, 2008. Participation was optional, the survey was estimated to take 30 minutes or less to complete and participants received a \$20 gift card to Walgreen's as payment for taking part in the study, as allowed by the UCSF Committee on Human Subjects Research.

B. Clinician Focus Group

The study consisted of a single focus group with medical providers (MDs and NPs) who worked in the SFGH Children's Health Center as primary care providers, and who may have admitted pediatric asthma patients SFGH in the past. Providers were invited to a one-time focus group with a meal provided, but no gift card incentives. Perceived causal factors for pediatric asthma hospitalizations by clinicians were identified using the same research questions for focus group discussion as used in Study I.

Study II Project Methods

A. Patient Family Surveys

Surveys were mailed four times total, each time to those who had not responded to earlier mailings. Written surveys in English, Spanish or Chinese were mailed to each family, according to the family's primary language on record. The cover letter explained to families that the project was to learn from the experience of families whose child was hospitalized for asthma to teach the Children's Clinic at SFGH how to help other families.

As relevant, all survey questions provided for multiple answer categories to be selected per question and additional space for write-in responses that might differ or add to the designated response categories. All data was considered subjective and the intent was to establish the family caregiver's perceptions in answer to survey questions.

B. Clinician Focus Group

In Project II, ATF used the same facilitated format as was used in Project I. Providers were offered a meal, but not gift card incentives. Only one focus group was held in Project II, as compared to four groups in Project I.

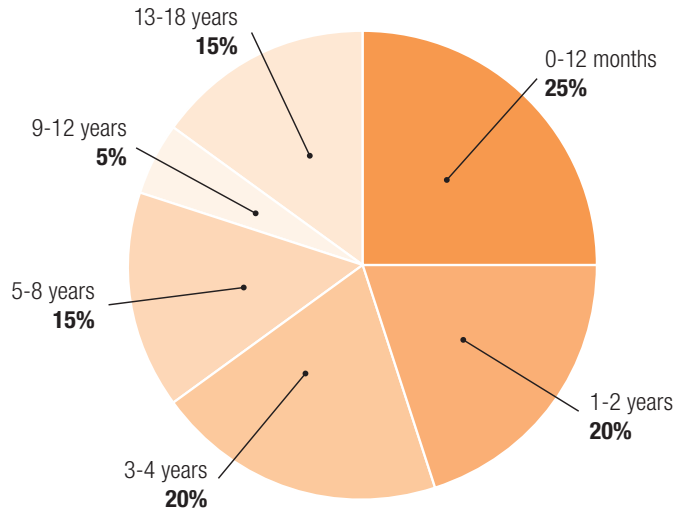
Analysis of the focus group qualitative data included qualitative descriptions by theme by ATF's qualitative evaluation consultant, Alice Hu, MPH. The audio-taped discussion was coded for themes, by importing compiled transcriptions into text analysis software. The themes included the perceived causal factors of hospitalizations, barriers and challenges to preventing hospitalizations, the cultural and linguistic appropriateness of current asthma care, the contribution of psychosocial stressors such as domestic and community violence as barriers to effective asthma management, and interventions or changes to decrease hospitalizations of children for asthma.

Study II Patient Family Survey Responses

Respondents:

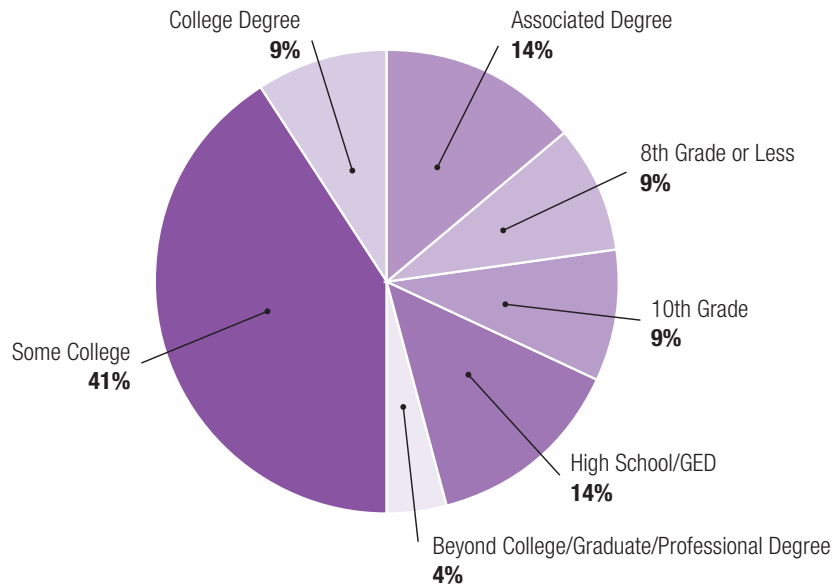
Surveys were mailed to 104 families of hospitalized patients, 93 who were San Francisco residents and 11 who were not San Francisco residents. A total 25 recipients completed and returned the surveys (24% response), with 92% returned from San Francisco residents vs. 8% from non-SF residents. Surveys were completed and returned as follows: 13 surveys completed on 1st mailing, 2 completed on 2nd mailing, 6 completed on 3rd mailing, and 4 completed on 4th mailing. 74 % of the respondents identified themselves as the mother of the patient and 9% as the father of the patient and 4% as foster parents.

Age of your child at the time of hospitalization for asthma. N = 20



The top two race/ethnicities completing and returning surveys were: Hispanic (61%) and African American (33%). The primary languages spoken at home were English (58%) and Spanish (42%). Respondent level of education is shown on the figure below, indicating that respondents had an educational level that included some college attendance (41%), an associate degree (14%), a high school/GED degree (14%), or a college degree or higher (13%).

What is your highest level of education you have completed? N = 22



Key Findings:

- The majority of respondents stated their child was less than one (23%), between 1-2 years of age (15%) or between 3-4 years of age (15%) at the time of their hospitalization.
- Cold, virus or flu was identified as the top reason for hospitalization.
- Increased coughing and wheezing as well as cold, virus and flu were identified as top observations of the child in the days leading up to the hospitalization.
- 52% of the respondents said they and their doctors understood the reason for hospitalization.
- 58% patients were taking medication at the time of hospitalization; most were taking both albuterol and controller.
- Only 56% of patients had seen an asthma specialist, mainly the SFGH Pediatric Asthma Clinic, highlighting the importance of asthma specialists.

Asthma Resources Received:

- Approximately half of the parents stated they were not referred to resources on how to manage their child's asthma prior to the hospitalization, the majority (74%) of parents were provided resources on how to manage asthma post-hospitalization.
- When asked about resources that they found to be helpful, 25 respondents indicated that these resources were the most helpful: nebulizer (12 times), spacer (9 times), mattress/pillow allergen cover (8 times), extra medication for school (6 times), peak flow meter (6 times), and asthma class or consultation (6 times).
- Family members were also asked to indicate what type of resources would have been helpful to receive. Allergy control products were most desired (12), followed by education about asthma (11), help with transportation (6), permission to leave job for child's medical appointments, providing services in my language (4), help with paying for medications (3), and extended clinic hours (3). Write in responses included: "Braille" and "nothing, maybe a hot line".

Peer-to-Peer Advice:

The survey established how the hospitalization experienced by these families might shape how they would advise other parents to potentially avoid their child being hospitalized for asthma. Respondents selected all answer categories as being important: Ask more questions of medical provider (16); Be more observant of changes in your child's behavior or asthma symptoms (17); Follow medical treatment plan and speak to doctor or nurse if it isn't working (17); Let your child's school/child care know about their asthma (12).

Social Determinants and Environmental Risk Factors:

In seeking to find out social determinants and environmental risk factors affecting asthma control, parents and guardians were asked "Do you think that there are other things in your child's home/school/community which may have contributed to their hospitalization?" Responses indicated with the most frequency included: mold/dampness (9), smoking (8), pests (7), stress in home (5), closeness to freeway or heavy traffic (5), and other (5).

Study II Clinician Focus Group Findings

Participants:

The nine focus group participants (including a mix of pediatricians and pediatric or family nurse practitioners) worked at Children's Health Center at San Francisco General Hospital and routinely offered care to children and youth with asthma. In general, all focus group participants expressed empathic understanding of the challenges faced by the low income families they served. Many comments from the Study II focus group replicated similar themes to those discussed by Study I focus group participants, and are shown in the relevant Discussion section.

Highlights:

Nurse practitioners and pediatricians in the focus group agreed that some pediatric asthma hospitalization is preventable, but not all because of these major issues:

- Uncontrollable environmental and social factors
- Access to health system, specifically one that can care for pediatric asthma
- Compliance to medication

Study I and II: Discussion of Patient Family Survey Responses



1. Patient education provided in the primary care setting should emphasize both proactive measures for asthma control and reactive responses to worsening asthma, in order to prevent asthma hospitalizations.

Medical providers generally provide patient education focused on proactive requirements for asthma control, i.e., compliance with prescribed medication use and avoidance of identified environmental or other asthma triggers. The October 2007 *National Asthma Education and Prevention Program Expert Panel Report 3, Guidelines for the Diagnosis and Management of Asthma*, recommends that clinicians provide to all patients a written asthma action plan that includes instructions for both daily management (long-term control medication, if appropriate, and environmental control measures) and actions to manage worsening asthma (what signs, symptoms, and PEF measurements (if used) indicate worsening asthma; what medications to take in response; what signs and symptoms indicate the need for immediate medical care). Responses from these patient family surveys indicate that parents did not necessarily know how to detect worsening asthma and how to act on those observations. For example, in the days leading up to their child's hospitalization, respondents in both studies were aware that their child had increased coughing or wheezing that they suffered from a virus, flu or cold, and that they woke in the middle of the night more frequently. They also noted decreased physical activity and/or greater fatigue and more sustained crying, with loss of appetite and thirst.

Based on these responses, the primary care setting should prioritize teaching family caregivers how to observe the specific warning signs and symptoms of uncontrolled asthma, in particular increased cough or wheezing, so that the child can be seen earlier in drop-in or urgent care as a means of preventing progression of uncontrolled asthma which results in hospitalization. This might be best accomplished in an audio-visual format. The teaching can emphasize that in young children, these developments most likely occur in response to colds, viruses and flus, because their lung air passages are very small and easily clogged by mucus. It should also be emphasized that night-time awakening due to cough or wheeze is a warning sign that should have medical follow up.

The 2007 *National Asthma Education and Prevention Program Expert Panel Report 3* also notes that the two major environmental risk factors that are the most important in the development, persistence, and possibly the severity of asthma are allergens (particularly sensitization and exposure to house-dust mite and *Alternaria*) and viral respiratory infections (including respiratory syncytial virus [RSV] and rhinovirus). Regarding the latter, note that San Francisco's low income families frequently must adapt to overcrowding in housing due to the lack of affordable housing. In addition, cultural practices for parents and children to share sleeping accommodations or for multiple children to share sleeping accommodations can increase the risk of respiratory infection and parents should be counseled that these practices can be modified during cold and flu season to prevent asthma episodes. Families should at least consider steps they can take to separate those who have colds or flu from healthier family members during sleep time.

2. Using patient families as peer educators via social media and print media is an overlooked resource. Parents provided insightful advice to other parents on how to potentially avoid their child being hospitalized for asthma, which included 75 total respondents from both studies advising others to:

Ask more questions of medical provider (36); Be more observant of changes in your child's behavior or asthma symptoms (57); Follow medical treatment plan and speak to doctor or nurse if it isn't working (50); and Let your child's school/child care know about their asthma (37). Other peer messages written in by patient family survey respondents included:

- Be sure to avoid all contaminants (allergies) that may trigger a spell
- Act at first sign during the night and don't wait til morning
- Do not ignore lung sounds in breathing no matter how much it looks like a cold or bronchitis!
- If you see pattern of escalation, ask doc for meds
- Don't listen to MD if they don't hear wheezing, in bad asthma, you don't always hear this
- Should have insisted that the diagnosis was more than a virus - especially at the 2nd doctor visit
- Sometimes you cannot avoid it - waiting too long can be life threatening
- It takes time and a few events to understand how asthma behaves, our child didn't cough or wheeze and went '0-60' from clinic to hospital visit in same 12 hours; it took us a while and a few types of medication to "get it"
- Learn how to detect wheezing, look for all the signs that are attached to asthma
- Take medicine to the school or child care for your child
- Prevention of attacks helps prevent asthma from getting more serious, if your child is having frequent attacks, demand to know more about non-steroidal controller medications that can help prevent attacks

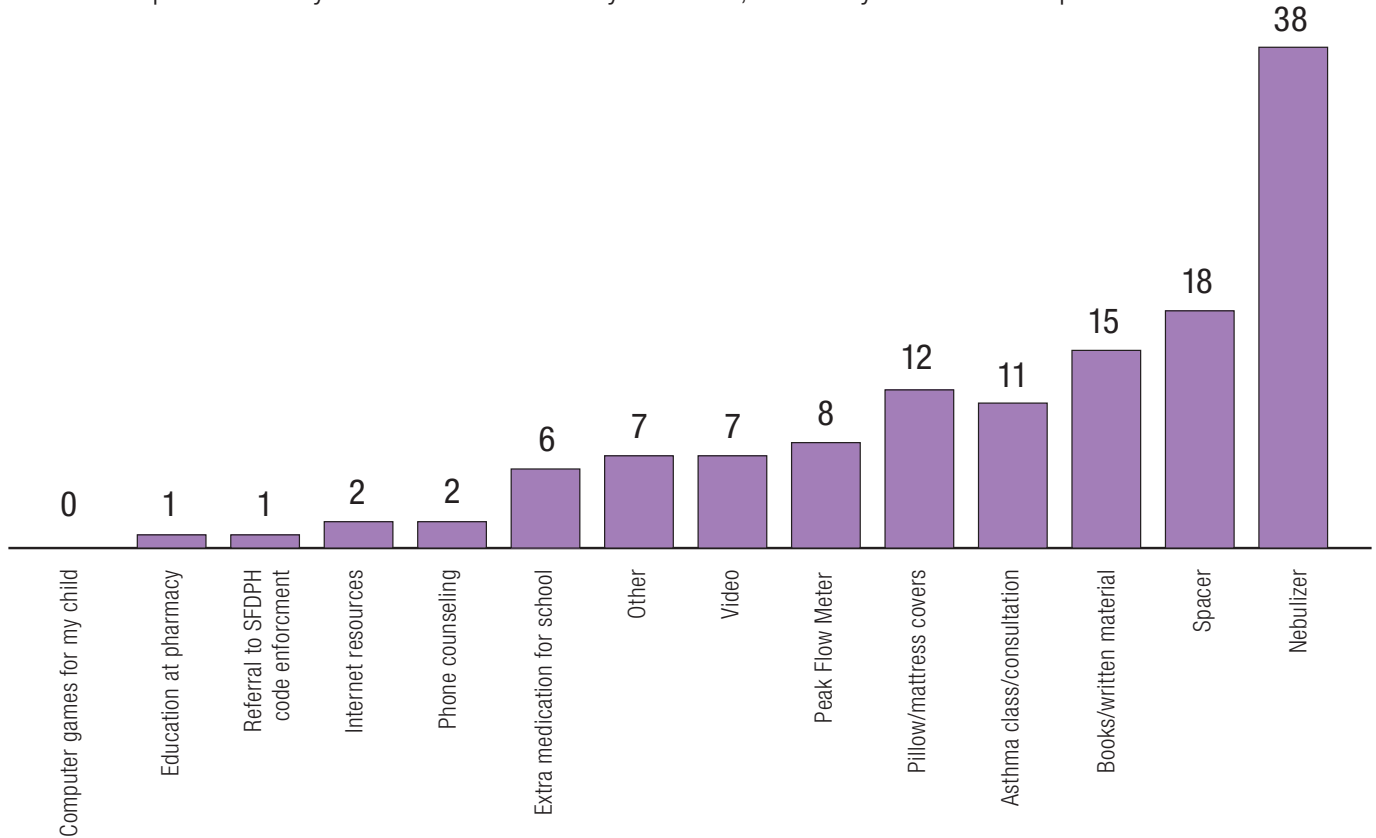
3. Families of hospitalized patients appreciated resources and education about controlling asthma and preventing asthma episodes, which is in contrast with how study providers perceive family receptiveness to asthma education prior to hospitalizations. Also families stated that these resources were provided more often following a hospitalization than prior to a hospitalization.

Families participating in CPMC Campuses Study I appreciated brochures on identifying risk factors, consultation provided with either pulmonary or allergy specialists, extended urgent care clinic hours and the "Decision Power Health & Wellness" complimentary benefit available to Health Net members which allows them to talk to a Registered Nurse 24 hours a day, to obtain support for any health situation.

SFGH patient family respondents in Study II greatly desired both allergy control products and education about asthma. Again, audio-visual training or hands-on demonstration of supplies and tools by auxiliary medical personnel would be desirable. They appreciated access to resources such as controller medicines, nebulizers, spacers, mattress/pillow allergen covers and written illustrated guidance about environmental risk factors to avoid. Families were also eager to obtain extra medication for school, peak flow meters and asthma class or consultation. Providers will need to assess each family's barriers to obtaining and effectively using such resources. We also learned that we are lacking asthma education resources in Braille.

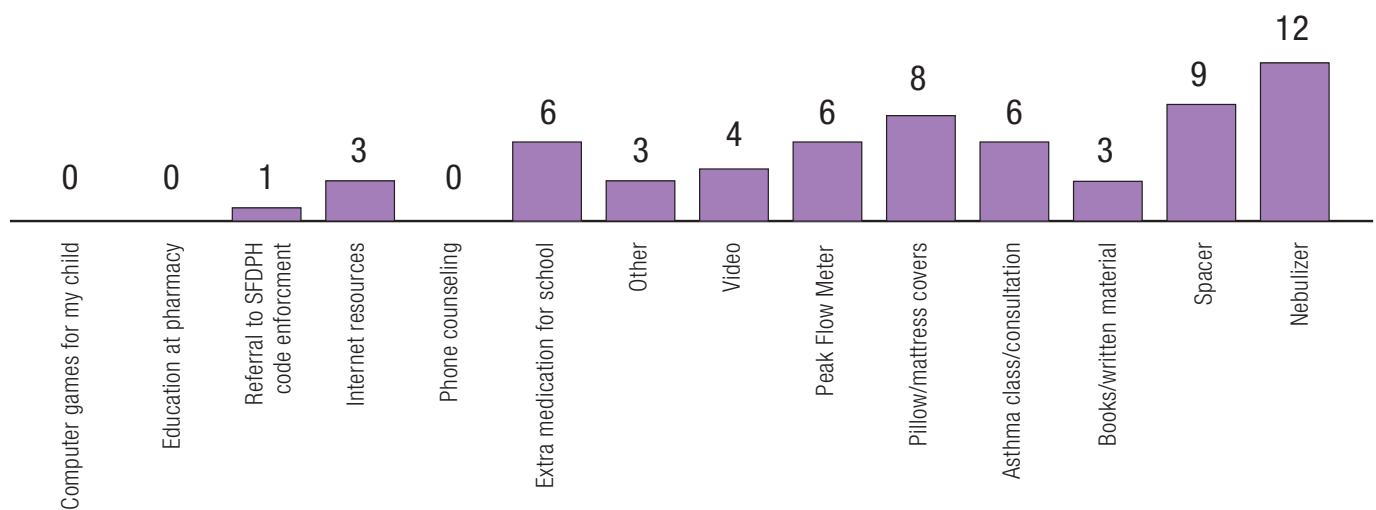
Study I (as reported by 50 respondents)

No. of responses for “if you received and used any resources, what did you find to be helpful?”



Study II (as reported by 25 respondents)

No. of responses for “if you received and used any resources, what did you find to be helpful?”

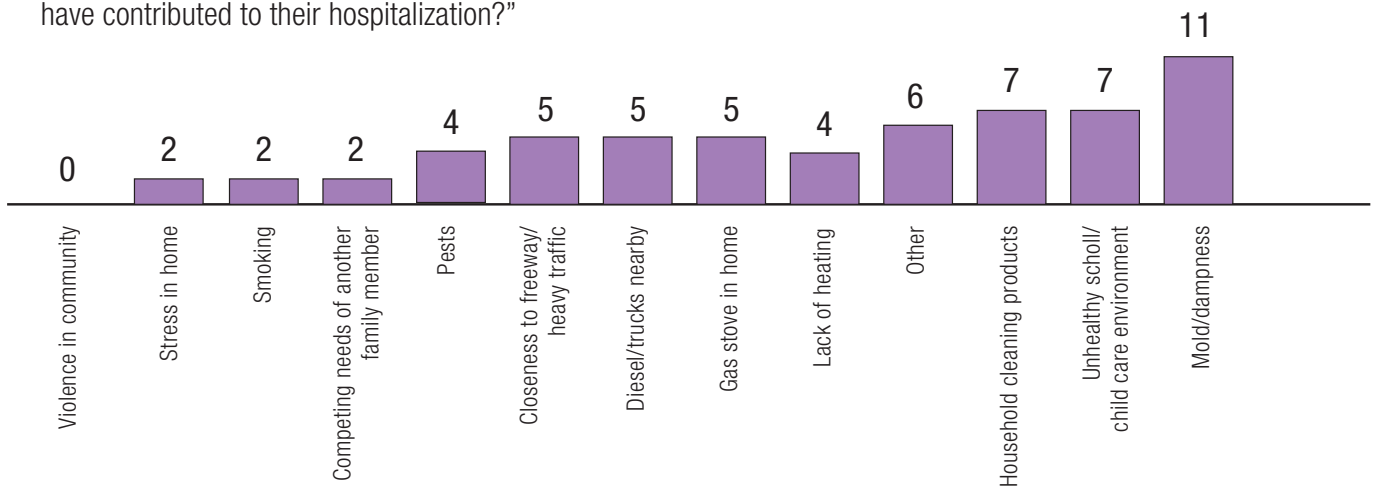


4. Environmental risk factors are present for families of children hospitalized for asthma.

Respondents in the two studies differed in how they ranked environmental risk factors for asthma and social stressors as potential contributors to their child’s hospitalization. For example, CPMC California campus and St. Luke’s campus respondents as a group ranked mold/dampness, unhealthy school/child care, and household cleaning products as the leading contributors to their child’s hospitalization. In contrast, SFGH respondents as a group ranked mold/dampness, smoking and pests as leading contributors to their child’s hospitalization. Additionally, one SFGH respondent felt that freeways should not be built and heavy traffic should not be allowed in proximity to residential housing. These responses sharply indicate the extent to which mold and dampness affect asthma patients citywide in both studies, with parents of all educational levels and race/ethnicities, and the need for resources on how parents can address this issue.

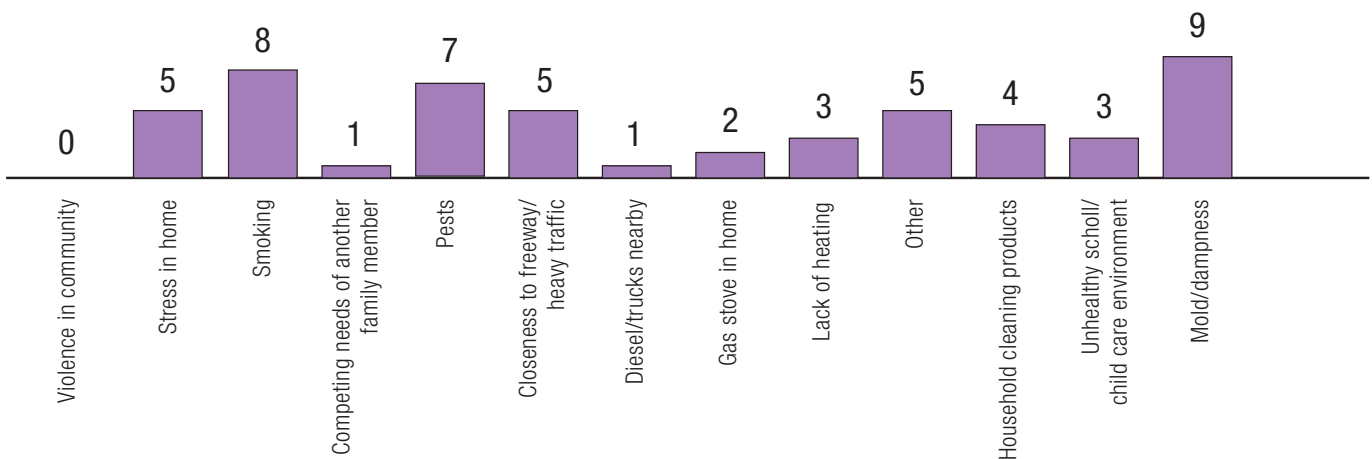
Study I (as reported by 50 respondents)

No. of responses for “Do you think that there are other things in your child’s home/school/community which may have contributed to their hospitalization?”



Study II (as reported by 25 respondents)

No. of responses for “Do you think that there are other things in your child’s home/school/community which may have contributed to their hospitalization?”



5. Social determinants of health still play an important role in how well families can provide proactive medical care to their asthmatic child.

Respondents in both studies commented on specific social determinant and economic risk factors for which they would have liked to receive support:

- “The cost to see the specialist was so expensive, it was not fully covered by insurance, we could not afford to go on a regular basis”

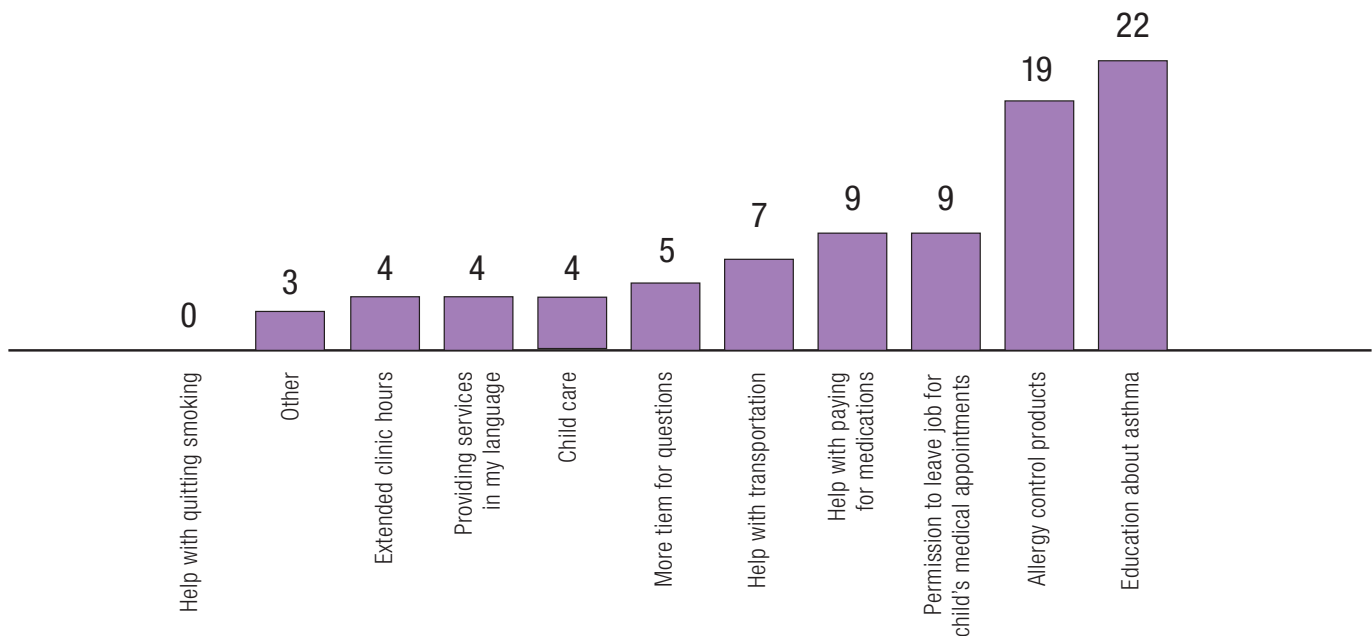
Respondents indicated additional barriers and desired resources to help manage their child’s asthma:

- Permission to leave work for their child’s medical appointments
- Help with paying for medications, as provided by prescription access plans for low-income individuals
- Help with transportation, as can be provided by Medi-Cal managed care plans
- Services provided in primary language
- Extended clinic hours

While most medical offices do not provide social services support, they could obtain information to share about how patient families can access social support services managed elsewhere.

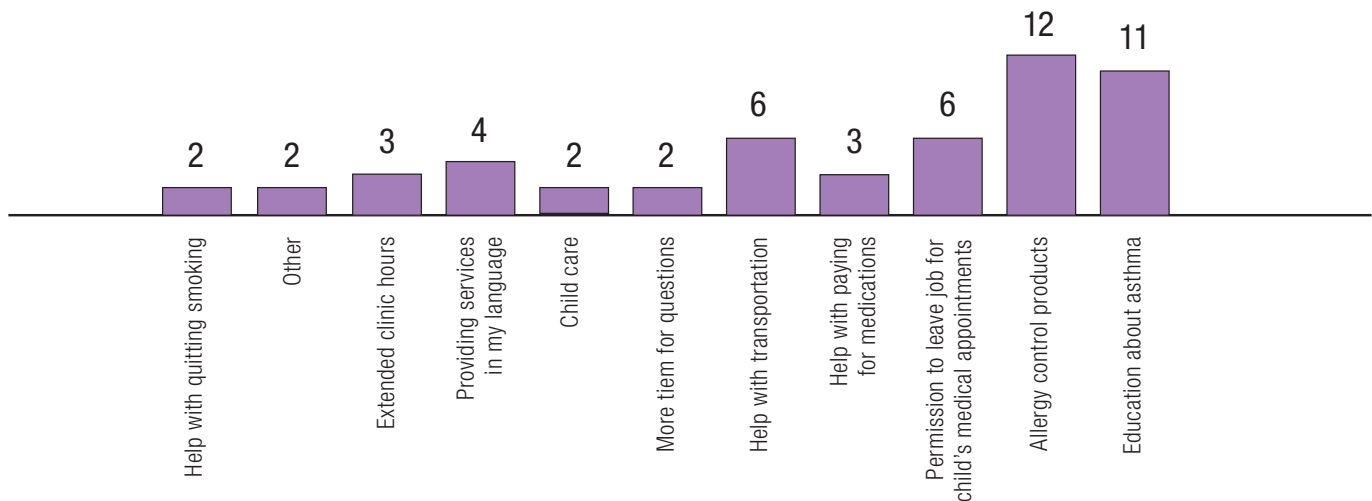
Study I (as reported by 50 respondents)

No. of responses to “What type of resources would have been helpful to receive?”



Study II (as reported by 25 respondents)

No. of responses to “What type of resources would have been helpful to receive?”



6. Parents of children who have been hospitalized for asthma still have basic questions about how asthma works and apparently no structured way to get answers to such questions. In addition, some parents feel they may be judged if they have failed to be medically compliant, and thus may not be truthful with medical providers.

Here are examples of questions posed by CPMC Campuses Study I patient family respondents, of whom the majority had an educational level that included college attendance or a college or graduate level degree.

- When my child exercises and has difficulty breathing, is it considered asthma?
- Would a change of weather affect asthma? My child's asthma has not been a seasonal asthma for more than ten years.
- Although the living conditions and school environment have not changed, my child still has asthma episodes.
- A friend of my child comes to my house and plays with my child. Every time after this friend has played with my child, my child would easily have asthma. Would asthma be triggered by human contacts?
- Don't know how long one can use the nebulizer before it needs to be replaced by a new one, and what is the procedure for getting a new one?
- I would like to know how to go about seeing an asthma specialist.
- It takes time to understand how to/when to use rescue meds, my main concern is if there are any side effects of meds long term.
- The attack that sent our daughter to the hospital was our first experience with her having asthma, we did not realize that her symptoms were from asthma instead of just the upper respiratory infection.
- When asthma happens, it is safer for a child to stay in hospital, especially at the time when a child, who is seen to have difficulty breathing, cannot accurately describe his own condition. Hospitalization is particularly needed at night time, when it is difficult to contact the child's regular doctor.

These are comments to the open-ended portion of the survey, from SFGH Study II patient family respondents, the majority of whom had attended some college, or had an associate or high school degree:

- “Sometimes it is difficult to remembering to give medicine, maybe come up with suggestions. Parents aren't very truthful about when we forget to give medicine, to doctors. At times, afraid we will be judged.”
- “If you don't have the money to buy the medication why can't the clinic give you one for free?”
- “When my child exercises and has difficulty breathing, is it considered asthma?”

Study I and II: Discussion of Clinician Focus Group Findings



1. Do you believe that it would ever be possible to prevent asthma hospitalizations?

CPMC Campuses Study I Clinician Focus Groups: While asthma is the leading cause of children's hospitalizations, there continues to be a downward trend in in-patient admissions. In general, the participants agreed that it's not common for pediatric asthma to be admitted to the hospital. Hospitalizations were more likely to result from a secondary infection along with the asthma.

The consensus of the focus groups revealed the perspective that there will probably always be children hospitalized for asthma. As illustrated by one of the participants: *"...I think that there will always be children hospitalized, I think the fact there's that influence that are so many including: the efficacy of the medications we use and the availability to kids, both the parents ability to administer these medications; there are environmental factors that we don't have control over, such as the upcoming potential spraying in our environment. You know, there are certain things we won't be able to completely control."*

SFGH Study II Clinician Focus Group: The group agreed that some pediatric asthma hospitalizations, but not all, can be prevented due to: a) uncontrollable environmental and social factors, b) access to the health care system, specifically one capable of pediatric asthma care, and c) compliance to medication.

One of the participants addressed environmental and social factors with this comment: *"I feel like even our most vigilant families have so many things outside their control. You can never fix those issues first." Another stated, "Our patients work, their families work two jobs. Most of the time, they aren't benefitted so they don't get sick time. Taking a whole day off work is huge, needing to get childcare whatever to watch the other kid. And we don't have weekend hours for primary care and most of us don't do nighttime hours and that is a big barrier for our families. Our most high risk ones they also have the really fragmented social lives and they can't be taking off. Every two months is very frequent for a lot of these families."*

Clinicians also wanted to go see for themselves what the home environment looks like to better understand the triggers. *"I feel like...it helps with our understanding and the patient's trust of us if we could get closer to the area."*

In regards to health care access, focus group participants said the following: *"We can never universally prevent pediatric hospitalization for asthma because of access to healthcare in the United States."* Clinicians desired having more practitioners in the clinic that could match the language and culture of the patient population. They also felt some patients require more time and encounters than are typically allowed by the patient caseload. Participants acknowledged the support they get by having a co-located pediatric asthma specialty clinic, and realized that other settings don't have that support.

2. What are the barriers and challenges to preventing hospitalizations?

CPMC Campuses Study I Clinician Focus Groups: A number of barriers and challenges contribute to childhood asthma hospitalizations and continue to impede progress in the reduction of such hospitalizations. See Study I Clinical Focus Group themes and quotes under both A. Patient Barriers and Challenges, and B. Provider Barriers and Challenges sections below.

SFGH Study II Clinician Focus Groups: The SFGH-based clinicians in this focus group spoke to many of the same issues addressed in Study I. Many comments focused on patient barriers presented by uncontrollable environmental and social factors such as substandard public housing and pollutants, unreliable public transportation, lack of time off for their child’s medical appointments. Access to the health care system was a second theme that included barriers such as incompatible clinic hours, long appointment wait times, transportation time needed to get to the clinic or hospital. See Study II Clinical Focus Group themes and quotes under both A. Patient Barriers and Challenges, and B. Provider Barriers and Challenges sections below.

Themes from both CPMC Campuses Study I and SFGH Study II

A. Patient Barriers and Challenges:

Recognition of symptoms.

Parents lack understanding of the mechanics of asthma and awareness of the triggers. Due to this lack of knowledge, they may not understand the treatment and control of asthma in their children. Non-compliance with asthma controller medicine was identified as a contributing factor for hospitalizations. This theme is illustrated by the following Study I participants’ comments: *“Parents don’t understand the mechanics of asthma, why the child gets sick. They’re not aware of the triggers; they don’t understand the treatment and how to control asthma in general”* and, *“...I would add recognition of symptoms as being an important one.”*

A recurring theme in the Study I focus groups was the inability of parents and families to recognize asthma as a chronic illness that must be consistently managed to prevent hospitalizations. The “normalcy” of coughing reinforces the issue that parents do not recognize the symptoms of their child’s asthma. Often parents perceive a “little” cough as normal and do not manage their child’s symptoms. *“I know some cases may be that the child’s been coughing so long, and they think it’s normal and they’ll realize that you can actually not be coughing or not be waking up at night.”* Study I participant

Furthermore, there may be conflicting perceptions in the level of symptoms between parents and children. *“...Sometimes the parent says ‘oh he’s doing great and the kid says ‘no, I’m not’. Or vice versa, the mom says he’s coughing all the time and wheezing, and the kid says ‘no, I’m fine, I go out and I do things’ so it really depends, you can’t generalize.”* Study I participant

Misperceptions of asthma.

A common theme that was reinforced among the Study I focus groups was that asthma is not realized as a serious chronic disease. Throughout the focus group discussions there was a continuous theme that there is a social norm across families and communities that asthma is not as serious as diabetes. The *“little cough”* in asthma is perceived as “no big deal” as compared to the negative consequences of diabetes.

Parents' misperceptions of asthma are a barrier and challenge to asthma management in the prevention of hospitalizations. The lack of understanding of the seriousness of asthma was cited as a common misperception by the Study I focus group participants. The perception that a child will "outgrow" their asthma was a common misperception encountered by the participants. This is further supported by a parental perception that *"they used to have asthma as a child, and not anymore."*

"See diabetes is quite different than asthma. And there are many incidences that a child can outgrow 'asthma' too, so the public, not just Chinese population, they somehow hope and wish that this asthma disease will go away as child gets older. And no one wants bad news and if you tell them asthma is a chronic life-long disease, initially, of course, you go through denial and it's normal for the parents to not want to accept the diagnosis." Study I participant

"Most of my patients; parents perceptions is that their child will outgrow asthma. And so it's very disappointing when I tell them that they may or may not. So again, education is very important. And what I usually tell them is that when they stop taking their medications, they usually come back with exacerbations, but I always tell them 'every time your child has exacerbations, it really ruins your child's lung capacity.' And that kind of sinks in a little bit, and I tell them it's important to take that inhaler." Study I participant

"Cure" versus "treatment" was a common misunderstanding among parents. Parents may neglect asthma symptoms when their child acts "normal." Similarly, when the cough goes away, parents perceive their child as "cured."

"I think that people have a hard time wrapping their minds around the idea of 'chronic disease.' And so they have something and they either want to know that they are cured, or either they have the disease or they're cured. Sometimes it's hard to get people to conceptualize 'managing a chronic disease' because nobody wants to have a chronic disease. And so I think that is part of it. I saw that actually with my own dad who has asthma, who has a PhD in organic chemistry, who was prescribed his controller medicine and he takes them and wheezes every day. And he's like 'is it gonna cure me? If it's not going to cure me, I'll just keep going with how I am' and I have to say 'dad, you're going to have airway remodeling' and that's the only reason that he now takes his controller medicine, it's because he realizes that there is something bad that can happen, if he doesn't take it." Study I participant

Medication compliance.

The lack of compliance with medications was identified as a significant barrier in the prevention of hospitalizations. In general, parents may perceive asthma "events" as episodic (i.e., "once they're better, they stop;" "families want to know when to stop") and fail to compliance with the prescribed medication plan. Furthermore, parents may not comply with prescribed medications due to concerns about the side effects of prescribed medications on their children. *"People don't wrap their minds around chronic disease...need concrete reasons why to take meds; coughing at night is a huge symptom they ignore...use cough medicine to relieve."* Study I participant

"Well, it's because parents don't really understand or they don't know what to do, and if it's a cold, each time they give their child albuterol, the child got wild on them, and they don't want to see wild again. And they don't want to see wild in the middle of the night so they don't want to do it. And I have a number of people who will do Pulmocort as a first line of defense, because it doesn't make them as crazy. And you try to say 'no, no, no, that is a controller medicine, it's a preventive medicine, and it's not a fix-me-quick medicine. Albuterol is your fix-me-quick medicine.' 'Yeah, yeah, yeah, but it made him crazy.'" Study I participant

When the Study II focus group discussed compliance to medication, they had a similar sense of futility to that experienced by Study I focus group participants. They felt that the family or patient's limited understanding of asthma,

or personal perception of asthma, affects their vigilance and compliance, as illustrated by this comment: *“You also have the families where parents aren’t very vigilant with their kids or they don’t follow the regime or they aren’t compliant with the varieties (of medication) or education or the level of how much they understand the disease.”*

Study II participant

Of particular difficulty is that patients still need to take controller medication when they feel fine. One comment to this effect was, *“And I said ‘why didn’t you take your (name of medicine) even though it’s been 3 or 4 years of no episode’ and she (patient) looked at me and was like ‘oh!’ So in their minds no symptoms or symptom free (means) that they are so much better and they forget... It’s like with any condition when you don’t feel sick or have any symptoms you forget to take the medicine no matter how smart you are you just forget.”* Study II participant

Compliance with Action Plans.

A Study I theme that emerged was the frustration that patients lacked compliance with their asthma action plans. This theme was reinforced by the issue of the lack of patient compliance with asthma management and treatment. *“... Occasionally we’ll get the patient who says ‘you told us if he’s in the yellow zone, we gotta call you’ so occasionally we’ll have people actually using their asthma action plans, but most parents don’t. And we give them fridge magnets and we tell them to put it on the fridge, you know but most often they don’t.”* Study I participant

“Sometimes I find them on the floor or the elevator, going out on the end of the day. Or sometimes I always put a copy in the chart and when they come in the next time, I say ‘oh, did you look at your action plan?’ and they say ‘oh, yeah’ and some say ‘oh, I didn’t look at that, did I?’ So I ask if they’ve taken their Advair every day. And they say ‘oh, yeah, I forgot’ so it takes constant follow-up, going over it and over it...” Study I participant

Difficulty of administering medicines.

Other barriers noted by Study II participants were the difficulty in understanding the use of controller vs. rescue medicines and properly administering medicines. *“It’s really hard for the family to comply and take the medication we have right now... it’s like you’re asking the family to do something almost impossible even for little ones... so I think my view point is very pessimistic because the fact that I understand the difficulty of administration of medication at any age,”* and *“The spacer is great but it’s unwieldy.”* Study II participant

Understanding medication types.

In addition, knowledge of the appropriate use of asthma medications for patient compliance was a theme that emerged among Study I participants. Often patients and/or parents are confused with the difference between quick-relief and controller medications. The complexity of the medication regimes makes it difficult for patients to adhere to prescribed asthma management: *“Inhalers used to be different colors, but that has gotten complex now, you used to be able to say the ‘orange inhaler or the white inhaler.’ Now they screwed that up.”* Study I participant

“It’s the every visit issue. I wish all quick-relief were red and all controllers were green or something. Because they always mix them up and they tell you ‘it’s this color, or this color is the new inhaler one, or with this insurance plan, it’s this color.’ So, like all medications, that’s the problem, that nothing is consistently the same. And I don’t blame them for getting mixed up. You could’ve told them fifteen times that this is the quick relief, and you could’ve drawn pictures and written all the possible names, and so I don’t know the answer to that.” Study I participant

Parental fear and distrust of asthma medication.

Parental fears of long-term use of “steroids” were considered a barrier to compliance with medication use. Negative perceptions of steroids use portrayed in the media have raised fears that asthma medications will pose a significant risk to their child. *“Yeah, and a lot of people are afraid of the steroids. And I go over that and I say ‘Yeah, this is a steroid, but no, this is not Barry Bonds kind of steroid.’”* Study I participant

Many parents want to avoid unnecessary medicating of their child, as illustrated by this comment: *“But a lot of families, again, are very reluctant, you know they’re starting to get afraid of medicine and in the sense afraid of antibiotics, so that’s good, or less act to always want antibiotics. But on the other hand, asthma medicines, they’ve heard, have side effects and they’re very reluctant to start fast, again unless they’ve had a bad experience. And especially, it’s not only the uneducated, you have extremely bright, wealthy, highly educated people who are steroid-phobic who will do anything short of putting their kid on steroid.”* Study I participant

Some higher income families may seek out treatments that are perceived as “natural” as opposed to the “unnatural” use of steroids. *“But that’s when they end up at the holistic practitioner who’s gonna cure it with tincture or porcelain. You know to the 10 million delusions, and they’ll pay cash big time as one of my partners would say ‘you could get more stuff from looking in the sidewalk than you get in the little container they just paid \$150 for.’ But it’s ‘natural’ and steroids are not natural.”* Study I participant

“The other issue in terms of compliance is for people who have a deep mistrust of using medication they perceive as having long-term negative consequences so I’m sure all of us have taken care of children of highly educated parents who absolutely refuse to keep the kids on steroids regularly, inhaled steroids, because they are concerned that that’s not healthy. They are looking for alternative therapies and they might not be as effective in controlling the exacerbation.” Study II participant

Prescription coverage inadequate.

Medical coverage plans may contribute to the barriers and challenges that patients and their parents face in compliance with asthma management and treatment. Co-payments and medications that are not covered by family plans may pose a significant financial burden to already struggling families.

“I think, again depending on insurance coverage and stuff like that, for chronic medicines, it’s hard to get people to co-pay. And then there are some families who can’t afford Advair, and it’s not covered in their form. And so they won’t go there even if they need it, they just won’t because it’s an expense every single month. And finances are tougher for pretty much everybody except for the upper end. And so after a while when the perception of the child is okay, or really not so bad, it’s very hard to go refill those medicines again. And actually what I run into now is, clearly a family is using their insurance to try and get medicine for other people. And because I now am very very careful, all these refill requests that come in, I look to see when the Albuterol was refilled before, and if it’s been more than two in a year, then I actually call those people, and this one family has been refilling them every month and I haven’t seen them in two years. And they’re arguing with me that they need it and I say ‘no, I can’t refill it’, until I was promised that they’ll come in. but I know they were using it to refill it for other people. But in the meantime, I get dinged ‘cause I’m giving them too many. So ‘no, no, no, no, no Flovent.’” Study I participant

Study II participants understood that patients were running out of medication due to insurance coverage issues such as the packaging of less than a month’s worth of dose in a single device, as well as the lack of a count-down monitoring system on all devices. *“Well it’s like Qvar, there is only 100 in each inhaler and you’re expected to do two (puffs)*

twice a day, so there's only 25 days in one inhaler and they're filling it and insurance covering their next inhaler so in terms of compliance there's still every month a few days where they can't get their medicine.” Study II participant

Families failing to refill prescriptions.

Study II clinicians experienced many patient families that did not refill their prescriptions even though their children had many years of treatment, and wished that patients had access to automatic refills. *“I see where as the asthma clinic would send a follow up report and it will say ‘stopped taking medication after ran out one month ago’ and you know these children have been on it for 6 to 8 years and the concept still eludes them that you have to refill and that it's really easy to refill – it's not a big thing. The Walgreens knows where you live; they will always find someone to refill especially an asthma med.” Study II participant*

Caregiver constraints.

Multiple issues impact the ability of caregivers to maintain effective asthma management practices to prevent childhood asthma hospitalizations. The complexity of caregiver issues included: exchange of information among multiple caregivers; money; day-to-day care demands; time investment; housing issues; transportation; other family issues; denial. Follow-up on a child's asthma poses a considerable time and resource difficulties for families. If a child is “doing fine,” there is reluctance for parents to maintain follow-up appointments with the physician. They may request to have just a phone call follow-up. In addition, conflicting work schedules and inconsistency of caregiver contact (i.e., grandparents or nannies bring the child in and don't know the medical history) were factors that posed barriers and challenges for appropriate follow-up visits.

Inter-generational caregivers posed a further barrier in parents' understanding and recognition of asthma symptoms among children. Lack of knowledge about asthma triggers and recognition of the symptoms may be impacted by an older generation's definitions and perceptions of the illness: *“And it's from another generation, so the fact that the kid is coughing all day is not a big deal because that's what everyone did all the time and it wasn't considered a disease so it's the same thing.” Study I participant*

Caregiver income as a factor.

Income level may influence the barriers and challenges faced by families with an asthmatic child. Middle and higher income families do not generally experience the environmental (i.e., proximity to freeways, home cleanliness) triggers faced by those in lower economic situations. While higher income families tend to be more educated, they are more likely to be concerned about medications and drug-testing. They tend to be more attentive to their child and less likely to have tobacco exposures. Depending on their county, middle and higher income families are more likely to have marijuana exposure.

Follow-up care for a child with asthma tends to not be a priority among those with higher incomes. *“But you also have two parents who are working, who are struggling to balance their kids and their jobs, and the nanny, the caregiver, the grandmother, grandfather, or whoever's helping out, and the communication and all that. And that's probably why they don't have time for their follow-up and their schedules shift. If it's not their priority, they're not going to...” Study I participant*

“And there are very wealthy parents who are traveling or whatever and send the child with the nanny who knows nothing, or may not even speak English. And they're taking care of them, and they can buy all the medicines, it's not an issue, they can afford to pay for it, but it's like not on the radar screen.” Study I participant

Stigma of asthma, particularly for teens.

Teens' attitudes and behaviors were identified as a significant barrier and challenge in asthma management.

Inadequate compliance with treatment among teens is a significant barrier and challenge. It is common for teens to not use their inhaler properly (i.e., not around their friends) or puffing at the wrong time. *"One big problem that I see is how they use the inhaler. And you'll be surprised that a lot of them don't use spacers or aero chambers. Especially with teens, they don't want to bring those bulky, and bug plastic tubes. So every time they use it, they won't expect maximum effect because of the lack of chambers. But I find, in teens, especially with sports, they are more compliant than the non-athletic ones because they do want to be able to participate, and without the medicine, they can't."*

Study I participant

"I see more compliance for my teenage patients when they use Advair, versus if they use inhaler with spacer, because Advair is compact and an inhaler with spacer, they tend to get embarrassed about it. My son is not even a teenager, he's only 10 years old, and one time I tried to give him an inhaler and he refused, he says 'mommy, don't do this to me in front of my friends.' So I guess children do get embarrassed about it." Study I participant

Teens experience the same denial as parents and adults with asthma. Teens discontinue using their controller medications when they do not experience asthma symptoms. They do not perceive their asthma as a problem and they think they might outgrow it. In addition, teens may perceive marijuana as "safe" because it is viewed as an "herb."

"...I think that the only other issue that I see in teenagers is that, especially teenage boys, a lot of them smoke marijuana. And they don't really recognize the impact that has on the health of their lungs. You know, I think people understand it conceptually that smoking is going to be bad for your lungs, but people have this view that smoking marijuana is this natural herb and it can't be bad for you." Study I participant

Asthma may also be used by teens as a means to manipulate their parents (i.e., an excuse, psychological abuse to upset their parents). It was noted that teens that identify with one sole provider have more successes in their asthma management.

Study II participants discussed the stigma of chronic disease, and asthma in particular; *"There's still a stigma for some patients to say that their child has ASTHMA."* The stigma for teens was especially highlighted; *"Nobody wants to be different; they (teens) all want to fit in the same group and so if they have an issue that is going to make them different from their peers they are going to pretend that it doesn't exist. And asthma is one of those things, too."*

Study II participant

Cultural barriers.

The theme of cultural practices was identified in Study I as a barrier to the prevention of asthma hospitalizations. The diverse populations of San Francisco pose a challenge in providing cultural appropriate asthma management and treatment.

"We don't do spirometry in the office but we do peak flows on all the kids, which is a snapshot of spirometry. And a lot of our families are foreign-born. Either there is a language problem or just not a lot of medical sophistication so I usually use my action plans a lot. So I'll draw and look over it and see the yellow zone and look at how he is coughing and see how his chest is going in and out, and so that means you got to take these medications. I'll show them little models and pictures of lungs and airways, and repeat it the next time and the next time and the next time if it doesn't sink in." Study I participant

A significant Study I theme was patients' perceptions of asthma and medication use. The Chinese community's perception is that children do not "wheeze." In addition, cultural perceptions of medication use further complicated compliance with asthma treatments. San Francisco's Chinese community believes that taking oral medications is "nasty" and that western medications have plenty of side effects. In particular, they don't like to use steroids. More common traditional healing remedies include shark fin soup, birds nest, and eating placenta. Often Chinese families use both herbs and western medicine.

"If you want to take anything by mouth, they think they have chronic illness and they tend to not want to take it. Versus an inhaler medication, that's one thing because their child is really sick and they're going to have to take something by mouth. And the second thing is once you mention something about 'steroids' they just back off; they associate steroids with something nasty. ...Most of my patients are Chinese and they tend to associate oral medications with something 'nasty.' For example they associate a lot of Western medications with a lot of side effects. ... I've had patients that they like to eat shark's fin or bird's nest and they eat the placenta and told me that it worked."
Study I participant

The role of traditional Chinese medicine was viewed as a significant factor in parents' understanding of asthma care and treatment for their children. As noted by one participant:

"...a lot of us have little bit of knowledge, not a lot, at least for myself, at least we know the name of the medication they use in Chinese herbal treatment. I know some them is effective, and I'm pretty sure some of them has steroids in it too. But I cannot tell one from the other too well. But if the parents are from China, they are used to have both Western and Chinese herbs, given to the child at the same time. Because I volunteered at the Children's hospital outside of [names of Chinese city] every year so I watch how they do it and they would use both at the same time. So to parents, it's a natural way to treat illness. Of course, we are trained as Western doctors, so we don't know the herbs. And the mom sometimes from her own cultural background, she has good intentions and use both."
Study I participant

"Maybe in the Chinese culture, it's hard for them to accept their child has asthma. One time, I told the mom of a patient that child has wheezing and mom was shock and so angry, saying 'we don't have Chinese word', which is Chinese word for Wheezing. I think that's the kind of situation for some of them, that's why we need to emphasize the education. Chinese patients are afraid of long-term use of medications and they want to stop as soon as they can when they don't have to take it." Study I participant

Similarly, African Americans utilize traditional folk remedies to treat asthma. These remedies included Vicks vapor rub and fried green tomatoes placed at a person's feet.

Transportation barriers.

Lack of transportation was identified as a barrier for many families. As noted by one participant, families may delay treatment for their child until the exacerbation is significant enough to require emergency medical assistance and an ambulance is dispatched to the residence.

"I think a lot of our families don't have cars so if an exacerbation happens at night or in the weekends, it's kind of a thing where they're like, 'do we wait it out? Or do we try to take the bus? Or do we wait 'til it's bad enough to call 911 and then the ambulance will just come and pick us up', which there is way overuse of 911 in my population. But I think that's a big thing, transportation is a big thing because it's not quick; it's like what would be a hassle for me? To get up, and take the kid in the car and realistically, get the four kids up and get them in the car. Take them to wherever and then wait, they have to take them to the bus stop and wait for however long it takes." Study I participant

Social barriers.

Social norms reflect that asthma is not a significant issue that needs to be dealt with aggressively. Competing life crises of violence and substance abuse are primary concerns for patients who reside in lower income areas. *“So I think that impacts the quality of life for some of our patients, certainly we see a fair number of patients whose parents are actively using substances so we have a couple of moms who openly admit to having a pretty regular cocaine problem, or methamphetamines, and definitely, definitely marijuana, I can't tell you how many of our dads use it, they come into the clinic and I'm just like 'were you smoking weed in the car on the way over here? Did you not know you were coming to the doctor?' it's pretty bad, because I think it's kind of normative.”* Study I participant

“Well, I would say in my practice, for example, I recently had a mom who dropped the kids at the clinic and ran out and said 'I gotta stop the housing authorities from taking the boards off of my windows and doors' because apparently, they had boarded up their own house so that people wouldn't break in, 'cause the minute you leave the house, people will break in,' it's not funny but it's kind of funny that the mom is like 'I gotta keep my boards on windows and doors'. Because A) some families, the unemployed families come in more often but then there's some families who definitely don't want to leave the house 'cause they know that when they come back, they're gonna be robbed, probably by their neighbors, which is horrible. So definitely I would say violence or crime in the neighborhood, the sad thing is no light comes in, and no air flows in the place so it's like mold galore, the indoor quality is horrible because all the windows are boarded up.” Study I participant

Uncontrollable environmental factors.

Uncontrollable environmental factors were identified as a factor that exacerbates asthma in children and results in hospitalizations. The Study I participants identified a number of factors for childhood asthma hospitalization, including infections (i.e., pneumonia, cold virus), uncontrollable settings (i.e., daycare and schools), emotional overlays (i.e., problems at home or school), and environmental exposures (i.e., allergy season, spraying). One participant commented, *“I see a definite decrease in asthma exacerbations, and these days its due to severe cold, you have pneumonia on top of asthma exacerbation. Also, for young kids too, they're hospitalized more often and it's usually triggered by a cold virus.”* Study I participant

Environmental barriers were a theme that was identified as a potential challenge in the prevention of hospitalizations. Specific areas of concerns that were identified included air quality, exposure to secondhand smoke in the home, and housing factors (i.e., mold cockroaches, hygiene problems, and dogs): *“...about half of our families are Filipino, we have a huge Philippine population. And a lot of them are being cared for by grandparents and a huge percent of them smoke, especially grandpa and they just don't think about it.”*

“And then there's a whole different issue in the environment and how close they live to the freeway, how clean or not clean the house is, how many animals are running around, and how many people smoke, and that they don't care anyway, and that they smoke in front of the kid...” Study I participant

[Pollution in the Hunter's Point area] *“Yeah, that's a hard thing to tease out because there is a lot of particulate dust in the air because there's so much construction going on around there and then of course there's the issue about asbestos, the natural serpentine contain asbestos. And there's the pollution from the power plant, there's pollution from the diesel bus yards that are there. And there was a study that showed that if you live within a mile of a freeway, your risk of asthma increases seven times, and we're right at 280 and 101 so there are two freeways. And the great irony of it is since I've been working there, my own asthma has gone off the charts, I now have much more asthma symptomatology than I've ever had in my life, which is very interesting. So, I would say, anecdotally there are a lot of particular issues.”* Study I participant

B. Provider Barriers and Challenges:

Reimbursement.

A recurring theme among the Study I focus group participants was the time demands and individualized asthma treatment plans needed to effectively educate patients, parents, and families. Short office visits do not allow sufficient time to adequately educate patients and parents on asthma management issues, however extended visits are not always reimbursed. In addition, reimbursement rates are lower for Medicaid and HMOs. To further exacerbate the problem, patients do not keep their next appointments and cancel at the last minute.

Study I participants perceived that the role that primary care physicians play in childhood asthma hospitalizations has been increasingly replaced by that of hospitalists who provide treatment for asthma patients during urgent care, ER and hospitalizations. Hospitalists cannot spend an hour with families for asthma management education.

Provider shortages.

Study II clinicians also discussed how provider shortages lead to poorer quality of the patient-provider relationship and felt that the health care system in general has a lack of capacity to offer specialized care for pediatric asthma. *“I think the even bigger issue is access to healthcare in general as we just passed some legislation that there is going to be some requirements that everybody has access but we don’t have enough providers and primary care to meet that need so the wait times are going to increase for kids even if they are sick.”* Study II participant

Time management.

A significant barrier for Study I providers was the time constraints in delivering patient care. Providers may be a “one man show” and are not able provide the individualized time, teaching, and appropriate interventions within the allowable office visit time frame. An overall theme to patient education was the lack of time available to deliver proper asthma education.

“There is no time for education. We’re glad if we see patients every 5-10 minutes, especially during flu season, there is no time for patient education. And one time we did have a presentation that we showed all our asthma patients. And there was an incentive, we gave them pillow cases and mattress covers. And they did show up and we showed them the video and tried to educate them about asthma and the importance of using their inhaled steroids and proper techniques of taking their medications. And we only had one chance to do that.” Study I participant

Furthermore, there is limited insurance reimbursement for patient education on asthma management. While some clinical settings are able to deliver patient education in group or initial settings, the ability to spend the necessary time with patients exceeds the reimbursement schedules by insurance carriers. Initial extended visits can be reimbursed, however follow-up visits require considerable time for which the provider may not be able to bill for the time that is provided in patient education.

“The only insurance company I know that will help with education, either by a doctor or by a nurse specialist, is SF Health Plan. They have a cap per year and how much they pay per person for fee of service. It is a problem in many clinical settings, the provider, especially the physician, they don’t have time, but hopefully the health educator or nurse specialist can have some kind of group or one-on-one type education sessions. I know when they go to a pulmonologist, they have a team that work with them initially, and they get education from nurse specialist.” Study I participant

Provider-Patient interaction.

The dynamics of patient interactions was identified as a challenge for Study I providers, including unrealistic expectations and communication styles. Unrealistic expectations can result in problems between the provider and patient.

“... So that’s another issue of the poor perceiver. So there are some people who cannot tell that they’re wheezing. They don’t get it; they don’t know their body well enough to sense what’s happening. In Gary’s presentation, was that this child was a well teenager wants to scuba diving, but I’m a little hesitant to sign this form and I say ‘oh, I get these all the time, it’s fine, send him over’ and I was totally prep for that this is going to be a healthy kid and I’m going to check his lung function and it’s going to be normal and I’m going to ‘okay it’. And then his lung function was absolutely horrible, it had severe obstruction... and on a peak flow too...” Study I participant

Communication between providers and patients remains a source of frustration. While providers strive to educate their patients on asthma management and care issues, it appears that families “don’t get it.” Providers invest considerable time educating a parent and they don’t show up for the next appointment. One participant pointed out that there may be a disconnection between health care providers and the patient. A recurring theme throughout the focus groups was the potential benefits of asthma patient education.

Health communication barriers.

There was a perception by Study II participants that even extensive health education and communication about medical treatment cannot overcome parental desire to have their child outgrow asthma and be cured. One participant commented, *“And we would like to think that education makes a difference, but I have the same problem with people I’ve sent to asthma clinic and maybe they’ve gone 3 or 4 times over a couple of years but still come away thinking perhaps the child will be cured because the child hasn’t had any problem in a while so therefore it’s (the asthma) cured. Education is part of it but it doesn’t necessarily change the behavior.”* Study II participant

Asthma care NHLBI Guidelines.

Asthma care guidelines were noted to have an excellent impact on managing asthma patient care.

“So we do this thing, which we’re really excited about, where we took the NHLBI guidelines, and I just have the little set of footcards that has the questions with step1, step2, step3. And we just did asthma intake forms with each age group and it has the NHLBI guidelines in a table on our form and I just circle them. And it’s very easy, and I say ‘okay, you’re coughing, more than twice a week, less than every day, and you have this and this’ and some people have mild or moderate categories, you know. Or you’ll see two of their things will be mild category, but one or two will be in the moderate category. And it’s great because then it says step1, step2, step3 and I say, ‘Okay, this patient needs to be on a) low-dose inhaled steroids with...I’ll be fabulous, it makes it very easy. I’m very proud that!’” Study I participant

“The author of the book ‘Asthma for Dummies’ came to our office to give a talk on asthma and he was saying that almost 98% of his asthmatic patients are on nasal steroids, because the partnering of the nasal and allergies and he has a better results with allergist and asthma control as well. So I’ve been using more and more of allergists. The book is really good, by the way. I recommended it to my patients, very practical and easy to read.” Study I participant

Use of spirometry.

A common theme across the Study I focus groups was the benefits of spirometry in patient education. Spirometry results can provide patients with a visual tool to demonstrate the effectiveness of medication compliance.

"I think, too, one thing that helped us is since we've been able to do the spirometry on our asthmatic patients, we are actually showing where we are now and then we see them if they're using their controller medication properly, then you see a big difference on the pulmonary function test. So it's been a big tool for us. And I think we're managing our asthmatic patients better than we have." Study I participant

"... What we've done now is that we have for every patient who either has a history of asthma or who we haven't seen for an asthma visit, or every patient who is newly diagnosed with asthma, they get a 40-minute asthma teaching visit. In that, we explain the patho-physiology of asthma, the medications, and the symptoms. We give them the handouts with all the teaching information and then we also do spirometry, so we do a pre-spirometry and then we do a bronchodilator and then we do a post-spirometry, as part of the evaluation, because many of the families don't really know if the child is just really out of shape, or whether they're asthmatic, or how bad the asthma is. And as I was saying before, there's often a huge difference in the report of the symptomatology and what the spirometry is. And so that's really helpful that we can see if they have reversible bronchiole restrictions." Study I participant

Peak flow meters.

In contrast, the use of peak flow meters was raised as a patient education and management strategy for patient education and assessment. Unfortunately, the use of peak flow meters has not been well supported in the asthma care guidelines. Peak flow can provide patients with immediate reinforcement on the importance of asthma care management. Several of the participants indicated that they use it as a training tool for "poor perceivers."

"... So we still used it for people who have trouble figuring out when they're sick and when they're not sick. It can be a very helpful guide for a young kid when they're able to do it well and when they're going off to different caregivers, they're now in their kindergarten or 1st grade, they have multiple people watch what's happening and they have a hard time figuring out the symptoms. So I think it can be a helpful device. I think insurance companies don't want to pay for them; families also don't want to pay for them. I get a lot of free ones, so I just give them out."

Study I participant

"I get the occasional teenager that uses their inhaler all the time when they don't need it too. And then that group, I try to teach them 'look, if your peak flow is okay, you don't really need this' I think it helps them too."

Study I participant

"I use peak flow and ask them to write it down before they come to the office, and it really depends on the patient, some patients are compliant and they do it for a whole two weeks or whole month. And some patients are haphazard, sometimes they do it and sometimes they don't. And the parents say 'see, you should be doing it.' But the parents are usually not involved, they're hands-off." Study I participant

Home assessments.

In addition, home assessments were identified as needed to address environmental triggers for childhood asthma. However, time constraints and lack of reimbursement prohibit individual providers from conducting assessments for their asthma patients.

3. How can we prevent asthma hospitalizations? What are the steps involved?

CPMC Campus Study I Clinician Focus Groups: While it is not possible to prevent all admissions, there was a consensus among the focus groups that it was possible to prevent some of the hospitalizations. The participants identified several preventive factors that have contributed to the reduction in hospitalizations, including better control of childhood asthma, decreased exposure to secondhand smoke, health education, and the pulmonologists/allergists work with the family and the child. As noted by one of the participants: *“Mainly, by so many things: education of the families; in terms of allergen control; in terms of smoking; in terms of taking appropriate use of medications. That’s the first...things that come to my mind.”*

Patient family education.

Patient education with spirometry results was identified as an effective tool with asthma patients. However, use of peak flow meters with asthma patients has not been as effective in patient education. Patient compliance with peak flow measurements tended to be “haphazard” and sporadic.

Access to evening and weekend urgent care.

Utilization of hospital emergency rooms was a key issue among childhood asthma. Access to urgent care, especially on evenings and weekends was identified as a potential method to reduce asthma hospitalizations. As noted by one participant: *“...Having access to urgent care, maybe on the weekends or something like that, so that families don’t feel like they have to go to the emergency room, ‘cause a lot of families will delay care if they feel like they have to go to the ER because they want to avoid waiting for so long.”*

Accurate family assessment of the degree of asthma severity.

Often families do not realize the severity of their child’s asthma. Aggressive management of symptoms was identified as a mechanism in the prevention of hospitalizations of children with asthma. As one participant commented, *“I think the biggest thing is that it takes a while for families to get used to the idea of aggressive, fast early-management of symptoms. Unless parents have seen a bad attack, they are reluctant to start medication early enough when they think that they it might be “just a cold.” And it takes a lot of education to try and get them to the point where they will be aggressive early.”*

SFGH Study II Clinician Focus Group: Prevention strategies were proposed in the same categories named as barriers: uncontrollable environmental and social factors, access to health care system, specifically one that can care for pediatric asthma, and compliance to medication.

Increased environmental and social risk factor controls:

- Improved access to habitable housing
- Enforcement of second-hand smoke regulations
- Reduction of second-hand smoke migration in multi-unit housing

Improved access to health care system:

- Drop-in, neighborhood-based clinics with flexible hours.
- Make sure that there are enough practitioners that speak the languages of the patient population.

- As needed, more time for patient encounters and more frequent encounters, to build relationships with patients.
- Increased school-based asthma management and education by qualified health professionals.

Compliance to medication:

- Use educational messages that stress the severity of consequences from non-compliance, “*such as damage to their lungs that they can’t see but it affects growth or function later in life*”. Also stated, “*Sometimes you have to say ‘Your child can die from asthma’ and actually say...that the severity is that their child can clamp down, stop breathing and die.*”
- Conduct public and community outreach meetings to address the stigma of asthma, to hold question and answer sessions where people in the community can ask what they don’t understand about asthma. Meetings can also be a forum to find out “*What in the community in terms of housing and pollution are they more concerned about too because they feel more involved in their care as well.*”
- Conduct public media campaigns, such as creating television public service announcements about what is the purpose of asthma controller medicines, what is an action plan; “*There’s not much on TV about asthma. Everybody watches too much TV...that’s probably the easiest way (to reach) the largest number of people – large group education.*”
- Address stigma for teens by portraying people that teens look up to (e.g., entertainment and sports stars) who have asthma and use their spacer and inhaler. “*Stigma removal especially for the adolescents so I’m just picturing in my mind an NBA basketball player who on the sidelines uses his inhaler with a spacer and that would go a long way for the teenagers in our community for being more comfortable for using that type of (medicine).*”

Improved patient provider communication:

- Utilize technology and innovation to improve communication and education for patients, including reminders via cell phones as done for diabetic care, and computer or video games and programs for families and patients.
- Communication that doesn’t just focus on medication: recognize other factors in the family’s life and relate to the patient. “*Next time when I talk to them I won’t talk to them about what medicine to take but if there’s a possibility of moving someplace else or is there a possibility of talking to the landlord of getting rid of the mold...So I think these home visits are invaluable and offer another perspective of some of the barriers they have.*”

4. In a perfect world that you had control over, how would you begin to prevent children's hospitalizations for asthma?

CPMC Campus Study I Clinician Focus Groups: The participants indicated that they would refer patients to pulmonologists for allergy testing. *"...I'll refer kids to an allergist and/or pulmonologist when the things I'm doing aren't working or if we've gone through all the steps and we're monitoring their meds and make sure they're inhaling correctly, or whatever. If all the tricks I've tried doesn't work, if we're having problems, I'll send them out to let the allergist see what they can come up with or pulmonologist to make sure I'm not missing some disease."*

"...sometimes you can 'smell' that this family needs extra help, so I will refer this family to the pulmonologist because they do have a comprehensive team to work with the patients, they have medical translators. So once parents get to a specialist, they tend to comply a little bit better, not 100%, but they comply better. Sometimes they get better so it's every three months with pulmonologist, then later once a year. So intuitively, as human being, we all know which family need to see a specialist and those are ones that we worry about, those end up in hospital more, and hopefully when they work with specialist, we get better compliance."

A concern raised was that referrals were sometimes too far from the clinic. However, referrals for allergy testing are not routine and reserved for those patients who need more or have additional medical conditions (i.e., GERD).

Regular follow-up care was also identified as a method to ensure that children would have consistent management of their asthma. As with diabetes, it would be advantageous to require regular check-ups regardless of the patient's present status (i.e., "feeling good or not").

SFGH Study II Clinician Focus Group: Prevention strategies were proposed in the same categories named as barriers: uncontrollable environmental and social factors, access to health care system, specifically one that can care for pediatric asthma, and compliance to medication.

Uncontrollable environmental and social factors.

These focus group participants were strong advocates for better housing, better enforcement of regulations that limit exposure to second-hand smoke, and less pollution impacting their patients. They noted second-hand smoke migration from outside and from adjacent units as an issue frequently voiced by patients living in public housing apartment buildings. Most succinctly, one participant stated, *"How about just solve poverty so that everybody...if they can move out of the area, they can. If they can get better housing, they can."*

Access to health care system.

One participant thought of a drop-in clinic with flexible hours, *"I was going to say I think one might be able to prevent hospitalizations if we had set up here a come and go clinic where a kid can be temporarily admitted as you will to be monitored and taken care of."* Another solution proposed was for neighborhood-based clinics so that families do not have to take two to three buses to the clinic or pharmacy.

Additional attention was placed on helping children with asthma at school, *"What about school-based care, that seems like an easy way to prevent...kids have almost universal attendance. I would put one of our excellent nurse practitioners in every school. We don't need fancy resources. A community health worker and a really good NP in every school in American who could educate families and provide medication."*

A clinician participant mentioned wanting to give clinicians opportunities to “*See for themselves what the environment looks like and...figure out what could be the triggers. I feel like...it helps with our understanding and the patient’s trust of us if we could get a closer look to the area.*”

Another participant advocated for more specialized care, such as that offered by Asthma Clinic, but also by changing how pediatric emergency care is delivered: “*And also institution specific and pediatric ERs devoted just to kids. I feel like they get thrown into the mix down there and it’s traumatic and if there was a separate place just for Peds (Pediatrics), some of those kids don’t have to be admitted, they might be able to be taken care of.*”

Compliance to medication.

Clinicians felt greater access to technology and innovation for communication and education would help improve patient compliance to medication regime. “*Computerized programs, so if you have something like that so if we have time you can sit down with the family to go over the learning plan and kind of explain to them some of the important points so you have a little bit of a tool to work with family besides kinds of yap yap yap (talking)...*”

Secondly, clinicians advocated for automatic refills for medication, particularly as parents often don’t understand that each prescription is authorized for multiple refills. “*I think the refill is a big thing. A lot of parents don’t get the concept. ‘Oh, we have a refill on it?’ ...they ran out of the med but you have six refills on your (prescription)...so in terms of just being able to get their medication automatic refill or something like that because you know they are going to need it.*”

Additionally, clinicians advocated for manufacturers to design better asthma medication delivery devices, based on their knowledge of patient barriers to obtaining correct dosage.

5. Are there ways that the Asthma Task Force can create or advocate for interventions or changes that may lead to a decrease in hospitalizations of children for asthma?

CPMC Campus Study I Clinician Focus Groups: Asthma education was a key theme and recommendation identified by the focus groups. The focus group participants suggested a number of specific asthma educational strategies that would increase awareness and knowledge of their patients. These suggestions included:

- Educational materials – develop handouts that are simple, informative, that could be given out the patients with visuals (i.e., depiction of an asthma-friendly room). In addition, handouts/fliers that target the spring and fall seasons. The National Allergy Supply was identified as a resource for teaching materials.
- Audiovisual resources – videos that could be used for asthma education.
- Resource guide – develop an asthma resource guide for patients. In addition, develop an assistance program that would coordinate and assist patients with asthma resources.
- Patient education – asthma education classes that are delivered in the clinics designed to involve patients and their families. Peak flow could be provided upon completion of the classes. In addition, provide education in the school and daycare settings to increase parent involvement.
- Community educational programs – extend asthma education programs to school settings to include teachers and students. In addition, develop public service announcements (PSAs) that provide education on all asthma issues.
- Home assessments – provide in-home environmental assessments for the family.

SFGH Study II Clinician Focus Group: This focus group did not devote much of their discussion time to making specific requests of the ATF. However, their stated desire to have educational materials that would motivate non-compliant parents could be met by having the Children’s Health Center utilize the YouTube posted public service announcement videos developed by ATF in three languages, which illustrate that children can die from asthma, and that asthma can be controlled. Secondly, a very well-produced CD music program, The Asthma Blues, developed to teach and empower school-aged children about asthma pathology and asthma self-management, is commercially available and successfully used by hospitals and clinics in other parts of the country. ATF can provide copies of the CD to any clinicians who would like to evaluate its effectiveness with their patients.

Study I and II: Clinical Interventions Related to Research Findings



A. Asthma interventions implemented by ATF Clinical Committee from 2003-2013:

While the two studies discussed have not directly led to new resource development, their findings did influence several other interventions of the Asthma Task Force during this same time period:

- ATF formed an Asthma Network for clinicians and asthma educators citywide, providing continuing education annually from 2006 to the present with support from Kaiser Permanente San Francisco, to improve the standard of clinical care and to build staff capacity for patient asthma education;
- With Kaiser Permanente San Francisco Community Benefits funding from 2007-2012, ATF helped several community safety net clinics build capacity for asthma management, education and quality improvement; asthma educators in these settings expanded their patient education to include chronic obstructed pulmonary disease (COPD) management and smoking cessation for adult patients; 2011-12 funding also allowed ATF to place a Community HealthCorps intern with the Balboa Teen Health Center to develop protocols that support students with asthma and overweight issues to become more aware of healthy living activities and better able to participate in physical education classes and sports;
- Asthma Resource Center of San Francisco, Inc., fiscal sponsor of ATF, has current asthma educator placed at Caleb Clark Potrero Hill Health Center, building registry and asthma standard of care capacity while providing individual and group asthma/COPD/smoking cessation counseling and establishing spirometry services;
- With UCSF Pulmonary partners and support from the SF Public Health Foundation, ATF promoted staff training and capacity to use clinic-based spirometry to diagnose and assess treatment of asthma patients; produced multilingual patient educational videos to coach patients how to complete an accurate spirometry test;
- SFUSD School Asthma Nurse half time position refunded with grants; ongoing collaboration with Pediatric Asthma & Allergy Clinic at SFGH, ATF and SFDPH in progress;
- With the Pediatric Asthma & Allergy Clinic at SFGH, ATF provided multiple translation, graphic reproduction and video production support for a multilingual patient orientation video and educational print materials; ATF also advocated for establishment of the Medical Legal Partnership clinic now operating at that clinic to pursue housing code enforcement and disability rights for asthma patients;
- With Board of Supervisors funding, ATF assisted 35 medical staff to become nationally-certified as Asthma Educators, and prepared over 75 individuals to take this exam.

B. Recommendations for capacity-building to address asthma disparities and unmet needs:

In addition to the opportunity to replicate or redirect those successful SFDPH clinical interventions in health care settings serving populations with the highest rates of asthma ED visits and hospitalizations, the San Francisco Department of Public Health could be solicited by the Asthma Task Force to take the lead in sustaining the following interventions to improve asthma control and prevention.

1. Promote resource knowledge base of primary care clinicians serving asthma patients from those racial/ethnic populations and geographic communities suffering asthma outcome disparities:
 - a. Link primary care clinicians to the audiovisual and web-based educational materials currently available for patient education, including:
 - i. ATF trilingual public service announcements about preventing asthma deaths, (<http://www.youtube.com/user/SFDPHVideo/videos?view=1>)
 - ii. Music teaching CD for children, The Asthma Blues, (<http://asthmablues.com/index.html>)
 - iii. ATF multilingual videos for patient coaching on spirometry, (<http://www.youtube.com/user/SFDPHVideo/videos?view=1>)
 - b. Link SFDPH and SF Clinic Consortium primary care clinicians to pediatric asthma specialty care available to patients by referral, through this multilingual orientation video:
 - i. SFGH Pediatric Asthma & Allergy Clinic, (<http://www.youtube.com/user/SFDPHVideo/videos?view=1>)
 - c. Link clinicians to SFUSD school-based asthma management program:
 - i. <http://www.healthiersf.org/Programs/SHP/Asthma/index.php>
 - d. Link clinicians to asthma home assessment services of SFDPH Environmental Health:
 - i. <http://www.sfdph.org/dph/EH/asthma/default.asp>
2. Reestablish defunded and maintain vulnerable asthma interventions and services still needed, such as utilizing AmeriCorps members as asthma educators for CHN and Consortium community clinics. The cost is approximately \$15,000 per AmeriCorps member per year. In FY 10-11 ATF placed Asthma/COPD educators at Chinatown Health Center, Curry Senior Center, Balboa Teen Health Center and affiliated partners: St. Anthony Free Clinic, Mission Neighborhood Health Center and North East Medical Services (several locations).
3. Establish network of asthma clinical champions who can meet to generate policy and practice response to latest research, and disseminate to safety net clinics and other providers; e.g., disseminate new policy based on ongoing review of research on the negative asthma impact from Tylenol use by children with fevers; see *Current acetaminophen and wheezing in children*, Etminan M et al., Chest 2009.
4. Fund new interventions addressing social determinant asthma risk factors, such as stress and emotional trauma. Create a citywide initiative to promote trauma-informed primary care, as trauma research has increasingly established that stress and trauma exposures are highly associated with lifetime inflammatory disease processes as well as with impacts on fetal development and later expression of wheezing outcomes in children; see *Disrupted Prenatal Maternal Cortisol, Maternal Obesity, and Childhood Wheeze: Insights into Prenatal Programming*, Wright RJ et al., Am J Respir Crit Care Med. 2013 Apr 3. [Epub ahead of print]

5. Replicate FY 11-12 ATF asthma/obesity prevention project with Balboa High School and Balboa Teen Health Center at all SFUSD high schools. Obesity is a risk factor for increased respiratory symptom severity in subjects with asthma. Research now exploring potential bi-directional causality between asthma and obesity presented at Dec 2012 CDPH *Asthma Research Summit*; see Holguin F, et al Am J Crit Care 2012, online.

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