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A multilevel perspective on goals, barriers, and facilitators of school-based asthma management

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Figure 1. Main themes across all interviews and supporting coding schema (synthesis map)

Conflict of interest statement

The researchers have no conflict of interest to declare.

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Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Quality in qualitative research statement

This study used COREQ criteria for reporting qualitative findings.

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Section, Paragraph

Domain 1: Research team and reflexivity

Personal Characteristics

- 1. Interviewer/facilitator Which author/s conducted the interview or focus group? Method, Data collection, para 2
- 2. Credentials What were the researcher's credentials? E.g. PhD, MD Method, Data collection, para 2
- 3. Occupation What was their occupation at the time of the study? Method, Data collection, para 2
- 4. Gender Was the researcher male or female? Method, Data collection, para 2
- 5. Experience and training What experience or training did the researcher have? Method, Data collection, para 2

Relationship with participants

- 6. Relationship established Was a relationship established prior to study commencement?
- 7. Participant knowledge of the interviewer What did the participants know about the researcher? Method, Data collection, para 2
- 8. Interviewer characteristics Method, Data collection, para 2

Domain 2: study design

Theoretical framework

- 9. Methodological orientation and theory What methodological orientation was stated to underpin the study? Methods, para 1

Participant selection

- 10. Sampling How were participants selected? e.g. purposive, convenience, consecutive, snowball Methods, Recruitment, para 1
- 11. Method of approach How were participants approached? Methods, Recruitment, para 1
- 12. Sample size How many participants were in the study? Result, Demographics, para 1
- 13. Non-participation How many people refused to participate or dropped out? Methods, Recruitment, para 1 - not tracked

Setting

- 14. Setting of data collection Where was the data collected? e.g. home, clinic, workplace Method, Data collection, para 1
- 15. Presence of non-participants Was anyone else present besides the participants and researchers? Method, Data collection, para 2
- 16. Description of sample What are the important characteristics of the sample? e.g. demographic data, date Result, Demographics, para 1 and Table 1

Data collection

- 17. Interview guide Were questions, prompts, guides provided by the authors? Was it pilot tested? eSupplement A
- 18. Repeat interviews Were repeat interviews carried out? If yes, how many? NA
- 19. Audio/visual recording Did the research use audio or visual recording to collect the data? Methods, Data analysis, para 1
- 20. Field notes Were field notes made during and/or after the interview or focus group? Method, Data collection, para 2
- 21. Duration What was the duration of the interviews or focus group? Result, Demographics, para 1 and Table 1
- 22. Data saturation Was data saturation discussed? Method, Data collection, para 2
- 23. Transcripts returned Were transcripts returned to participants for comment and/or correction? NA

Domain 3: analysis and findings

Data analysis

- 24. Number of data coders How many data coders coded the data? Methods, Data analysis, para 1
- 25. Description of the coding tree Did authors provide a description of the coding tree? Figure 1
- 26. Derivation of themes Were themes identified in advance or derived from the data? Methods, Data analysis, para 1
- 27. Software What software, if applicable, was used to manage the data? Methods, Data analysis, para 1
- 28. Participant checking Did participants provide feedback on the findings? NA

Reporting

- 29. Quotations presented Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number Throughout MSS; participant category identified with each quote
- 30. Data and findings consistent Was there consistency between the data presented and the findings? Yes
- 31. Clarity of major themes Were major themes clearly presented in the findings? Yes
- 32. Clarity of minor themes Were minor themes clearly presented in the findings? Yes

Abstract

Background: School based asthma care is being increasingly used to combat uncontrolled pediatric asthma.

Objective: The purpose of these secondary analyses was to explore multi-level perspectives regarding school-based asthma medical management for inner city, school-aged children with poor asthma control.

Methods: Sixty-six participants from 2 large U.S. urban school districts and key stakeholders participated in 1:1 interviews and focus groups. Participants were selected from across the asthma care community (children/caregivers, school personnel, nurses, pharmacists, healthcare providers, and administrators/insurers). Qualitative and descriptive techniques were used to analyze data.

Results: *Goals:* Children/caregivers prioritized living a normal active life with few asthma worries. Other stakeholders prioritized reducing student's asthma related emergency room visits and lost learning time. *Facilitators:* Continuity of care, strong relationships between care community members, and incentivizers were commonly suggested facilitators. School-based asthma management was viewed as a strong facilitator, particularly in the presence of a full-time school nurse. *Barriers:* Four themes were identified. (1) Greater systems and policy support for asthma management is needed in general, and at school in particular. (2) Overburdened families *and* systems often operate in crisis-mode, and asthma management is often not a priority until crisis is reached. (3) Discordance and distrust between members of the asthma care community can hinder shared asthma management. (4) Better communication is needed at all levels to improve care. **Conclusion:** Moving away from a crisis-based approach to

asthma management for high-risk children will require increased systemic support for proactive asthma care and optimized communication within the asthma care community.

Background

Nearly 11.6% of children in the U.S. have a current asthma diagnosis,¹ with half having chronically uncontrolled symptoms.² This is often attributed to suboptimal asthma management by patients and families, particularly with school-age children assuming responsibility for managing asthma at increasingly younger ages.^{3,4} Yet, asthma care for school-aged children (ages 5-17 years) still requires a network of individuals to support care.⁵ Historically, this has included caregivers, healthcare providers, pharmacists, and payers, and now also includes school personnel (hereafter collectively referred to as the child's asthma care community).⁶⁻⁸

School-based asthma care for administration of controller and quick relief medications has accumulating evidence of good efficacy^{6,8-12} and uptake of these programs is increasing nationally.¹³ A recent Community Preventive Services Task Force report offered strong support for school-based care (SBC) due to effectiveness in reducing hospitalizations, emergency visits, and burden of asthma, along with greater quality of life and health equity.¹⁴ Thus, with increasing adoption of SBC there is need for a contemporary, multidimensional understanding of challenges faced, so as to maximize long-term efficacy of these programs.

Prior research has established that children with asthma and families face numerous impediments to asthma management. These include lack of knowledge, limited access to care, attitude and belief barriers, and communication problems.¹⁵⁻¹⁸ However, little is known about asthma management challenges in the context of school-based care. To date, most research in this area has focused on efficacy, as measured by child health outcomes,^{6,8,9} or barriers and facilitators at family or provider levels, and does not account for stakeholder perspectives across the wider care network—which may partially explain the limited uptake of these important programs.^{17,18} Therefore, the purpose of this study, which focused on school-aged inner city

children with poor asthma control, was to understand multi-level perspectives of and experiences with school-based asthma management across the asthma care community, with an emphasis on identifying ongoing barriers.

Methods

This qualitative study was approved by University of Rhode Island (IRB2021-205).

Setting, sample

Participants were associated with two urban U.S. school districts that utilized school-based care (SBC) for asthma. In addition to standard school asthma care (i.e. rescue medication as needed), both districts had programs that enrolled children with poorly controlled asthma, and facilitated administration of controller medications at school via directly observed therapy (DOT). District A comprised 109 schools and 53,327 students; 79% were low-income, 14% had limited English proficiency, and 12.36% had asthma. Racial distribution was 56% Black, 26% White, and 9% Latino. District B comprised 31 schools and 20,435 students; 13% had limited English proficiency, 50% were low-income, and 12.37% had asthma. Racial distribution was 68% White, 13% Latino, and 12% Black.

Consistent with the Chronic Care Model (which postulates that health behaviors and outcomes are products of interactions at personal, interpersonal and systems levels),^{19,20} participants were purposively sampled from eight categories: children (**Child**), caregivers (**CG**), primary care providers (**PCP**), Pharmacists, school nurses (**S-RN**), home health nurses (**H-RN**), medication monitors (**MM**; unlicensed lay-personnel who administered prescribed medications), school secretarial personnel (**SP**), administrators from home health, school districts, and the National Association of School Nurses (**Administrators**), and the payor/insurer (**Payor**). Staff directly involved in supporting the DOT program were not included.

Recruitment, screening, eligibility for main study

Potential child/caregiver and school participants were identified by school and study staff (in person or via flyer) and screened for eligibility. Refusals were not tracked. Other stakeholders

were recruited by the primary investigator (PI) via email or phone. Caregivers and stakeholders were eligible if they spoke English and cared for a child with asthma who attended a participating district. Children were eligible if they spoke English, had a documented diagnosis of asthma on record with the school, received asthma care at school (usual care or DOT), and attended a participating district. School nurses, secretaries and medication monitors were eligible if they spoke English and participated in school-based asthma care.

Data collection

Written informed consent (adult) and assent (child) were obtained. There were no withdrawals. All focus groups were conducted separately in private rooms (school or community). As with other groups, children and parents were interviewed separately. Stakeholder interviews were conducted in individual offices. Participants received a \$20-30 gift-card incentive.

Demographic information was collected via paper survey. Interviews were conducted using semi-structured protocols developed specifically for each group (**eSupplement A**). Topics included perception of asthma, goals/priorities for asthma management, and barriers/facilitators of general and school-based asthma management. Interviews were conducted in 2016 by two white, female researchers: KA (pediatric asthma researcher, PhD), CM (school nurse and predoctoral student). Interviewer background was shared with participants prior to interviews. A PhD nursing student (ES) served as recorder, and field notes were taken. Interviews were conducted until data saturation was achieved.

Data analysis

Audio recorded interviews were transcribed, deidentified, and analyzed using Nvivo12. Coding was conducted by analysts unaffiliated with the original study (JS, JM, AP; ethnically

diverse females; advanced practice nurse, schoolteacher, nursing student). Consensus coding was used. Coding was performed in three stages, beginning with open coding. There was no *a priori* schema; all codes and themes were developed inductively from narratives.²¹ Pattern coding was conducted using mapping techniques to develop themes.²² This included clustering/merging similar codes, refining ideas, and developing a thematic structure.²³ Each participant group was mapped individually for group-specific themes. Thereafter, thematic maps were analyzed for similarities and differences within and across groups,²⁴ with reference to narratives, and a final thematic synthesis map and coding tree was developed (**Figure 1**). Peer debriefing and data triangulation were used to enhance validity.²⁵ Analysis was conducted prior to reviewing reports from the main study to maximize objectivity.

Results

Demographics

Sixty-six people participated: 16 children, 14 caregivers, 5 secretarial personnel, 7 medication monitors, 12 school nurses, 1 home health nurse, 2 pharmacists, 2 primary care providers, 6 Administrators, and 1 Payor. **Table 1** presents demographic and interview characteristics.

Key findings

In general, participants reported that SBC was highly beneficial but could be improved upon if multi-level systems challenges (i.e., divergent goals of care, multi-level systems barriers, difficult communications, and interpersonal challenges) were addressed. Perceptions and experiences were generally congruent across school districts, however, MM were only employed by District A.

Goals for asthma management

Table 2 shows asthma management goals by order of importance for each group, with each group prioritizing a different component of asthma health that often stemmed from their job/role. Children and caregivers were most concerned with the child's ability to live a normal active life, without worrying about asthma, whereas other stakeholders were more focused on reducing asthma-related emergency room (ER) visits and minimizing lost learning time:

Caregiver: My goal is being controlled. [that] doesn't mean [asthma has] gone away but to be at the worry-free zone...

Administrator: How can we help them better manage their health within the school setting so that they're in the classroom rather than out? I think that would be our primary goal.

Individuals in the healthcare field acknowledged potential conflicts between personal asthma goals and fiscal-based industry metrics:

Payor: "the craziness of the healthcare system is that children are actually less expensive if they're going to the ER periodically. To take [controller medicine] ... it's like \$2,500 a year [and] ...not many kids are using \$2,500 worth of ER visits, so...it's actually less expensive for them to NOT take their medicine and just show up in the ER ...[but] it's a terrible outcome for the child.

PCP: Maybe [we] shouldn't have to show return on investment... Don't try to do it on the cheap... it doesn't work.

Facilitators

Table 3 presents perceived facilitators of child asthma management. Facilitators fell into two categories – those *experienced* or observed by the participant, and those proposed or *hypothesized* by the participant. Most experienced facilitators were attributable to use of school-based asthma management. The most commonly mentioned facilitators were continuity-of-care and strong relationships between care community members. Incentivizing was also suggested as a motivator for children, parents, and even PCPs:

MM: I give my kids [rewards] ...and they make it a point to get to me ... But what would motivate a parent?

All participants felt SBC improved child asthma management and provided additional resources and support to struggling school staff and families. Specifically, SBC helped establish medication routines, supported adherence, facilitated refills, improved child self-management, and reduced adults' anxiety.

Administrator: one of the values of [school-based care] is the kids get structure [and] routine. ... [We] know that they had their morning treatment. Prior to this program, we didn't know.

Child: [Getting medicine at school helps you] stay on track.... It helps you breathe[and] feel better.

Most participants indicated that having a full-time nurse was important for effective and safe school-based asthma management:

SP: I'm so grateful for the time [the nurse is] there. I'm like, woo-hoo! Go see the nurse!

Administrator: But that's only if the nurse is in the building...

S-RN: "We need more nurses,"..."you don't want to [exclude] somebody just because we don't have anyone to give the medicine."

When a full-time nurse was *not* present to manage the asthma routine, school-based care sometimes resulted in inconsistent medication handling and created uncertainty, role-strain, and anxiety for both parents and school staff.

RN: We need to [be] sure who's responsible to get the medication ... If [the secretary] is doing it they're gonna have to leave their other job for 15 minutes to do the meds... [but] then somebody else needs to be the secretary.

SP: If the nurse isn't there [giving medications] falls on me—and I only have a nurse two days a week...So I'm pretty much I'm a nurse most of the time.

Caregiver: They offered this school-based thing to administer preventative medicines, but ...I administered myself because I've been at the school. The nurse ain't even in! One kid was having an asthma attack, [and the nurse] is not at school till 10:00!

Barriers

For this group of poorly controlled pediatric asthma patients, barriers to asthma management were identified at personal, interpersonal, family, systems, and policy levels (**Table 4**). Four themes were identified across groups: (1) Gaps exist in systems and policy support for asthma management in general and at school; (2) Overburdened families *and* systems operate in crisis-mode, such that asthma management is often not a priority until crisis is reached; (3) Communication challenges exist at all levels and may contribute to (4) discordance between

members of the asthma care community hindering collaborative asthma management. Minor themes showing the impact of personal beliefs and limited knowledge on asthma management at all levels of the asthma care community were also identified.

Theme 1: Insufficient systems and policy level support

Nearly all participants reported that insufficient support at systems and policy levels limited ability to deliver effective asthma care (**Table 5**). Barriers included shortage of resources (e.g. insufficient time to deliver care, funding for supplies, limited space to store/administer medications), unclear organizational policies (e.g. procedures for accepting medication deliveries from the pharmacy or administering medications when the nurse was unavailable), and lack of data to support institutional decisions related to asthma care. Many participants (CG, SP, School Nurses, Administrators) were concerned by the lack of a full-time school nurse to manage medications and acute asthma symptoms:

Caregiver: Another challenge is [not] having school nurses when they're needed. I can't tell my son, "You can only have a flare-up on Monday, Wednesday, Fridays between eight and twelve [because] that's when you have [a nurse]."

SP: We have [a nurse] scheduled three days a week [but] I saw one once this week ... We're not trained...what do I do? I'm not a nurse.

Lack of a nurse to oversee asthma care raised concerns about legal risks associated with performing actions outside of an individual's job description—most commonly in the case of secretaries or non-medically trained staff administering asthma medications.

Theme 2: Families and systems operate in "crisis mode" - Asthma isn't a priority

The second major perceived barrier in this cohort of poorly controlled children was the tendency to manage asthma "in crisis mode." This was reported at family *and* systems levels (e.g. school, clinic, hospital). A medication monitor explained of parents, "*if the child's asthma*

is not the crisis of the moment, then that's pushed aside because there's a different crisis that needs to be paid attention to." Similarly, a physician commented about the healthcare system, *"clinics are very, very busy and there's a huge schedule of patients to be seen, so people are just taking care of top priority, which may or may not be asthma at all—it may just kind of get buried."*

Often, asthma was often not a priority until an acute situation arose. This led to a cycle of reactive asthma management, which was fueled by lack of resources (e.g. time, money, personnel, and psychological reserves). As one Administrator expressed simply, *"They're overwhelmed."*

Caregiver: Just getting the medicines [is hard] and then they need to be rushed into the hospital and you've got to call an ambulance and if you've got the kids you can't take everybody...so you call a cab.

S-RN: mom can't get time off. [Asthma] isn't her highest priority...until it's a crisis...They schedule a follow-up, but once that crisis is over...They're not going to show up

SP: Phone's ringing, doorbell's ringing, parents are looking at me... students need their inhaler, oh my goodness, I'm trying my hardest to time it.

PCP: There's this whole line up of things [physicians] need to do every visit...there are problems that are more pressing [than asthma]... [and]we only have seven minutes...

Furthermore, the preventive asthma care available to families was often perceived as impersonal, inconvenient, or unattainable. For example:

Administrator: We say call your doctor...You call... you're on hold 15 minutes... so, click, they go.

Caregiver: We sat there five hours in the waiting room, and I was like, "Do I need to [leave and] come back?" They said, "If you [leave], it'll be three months before you'll be seen again."

H-RN: Parents are in survival mode ...the pharmacy is twelve blocks away, and walking is not an option [because of] gang activity.

MM: some [parents]aren't legal and they're afraid too much attention is going to get them in trouble. They tell the kids "don't talk about it, you don't have asthma"

PCP: it's terrible – it's non-personal, it takes a long time to make an appointment...[and]continuity of care is a disaster...they never see the same doctor... we have to go back to old-fashioned medicine which is continuity of care for chronic disease management, and we're missing the boat.

Similar comments were made about asthma education, which was usually provided to families during acute/emergency visits, and minimally absorbed:

H-RN: I'm not saying [asthma education] wasn't told to them, but they didn't receive it. If they're in crisis in the emergency room, you can guarantee they're not receiving that information.

Theme 3: Communication challenges exist at all levels

Communication between members of the asthma care community was another commonly reported concern (**Table 6**). As one PCP stated, "*communicating effectively...that's the first barrier.*" Disruptive communication existed between and across healthcare providers, school personnel, hospitals, parents, and children. For example:

S-RN: [Parents] are primed to not answer us. They think they're in trouble or they're afraid the kids are in trouble.

Legal policies were also felt to adversely affect communication and care, most commonly, by legal limitations imposed to protect patient privacy and confidentiality:

Administrator: there's confusion about HIPAA and FERPA—what can we share, what can't we share? Couldn't we just go back to the old days where we could just talk?

Although access to a shared EMR was desirable to many for improving communication, some felt it posed further legal risk:

Administrator: I'm not sure I want to [share records]... if we have access but we don't have time to look that day ... are we legally liable?

Theme 4: Discordance between members of the asthma care community exists and may negatively impact collaborative asthma management

Discordance between care community members arose due to personal and group differences in role expectations, training/education, approaches to asthma management, and beliefs about asthma (**Table 7**). This concept was broadly coded as "Us" vs. "Them" based on the nature of multiple passages where individuals referenced a personal or group perspective/position and then highlighted differences between the perspectives/positions of a different group, as illustrated by the quotes below:

CG: You all feel like it's a [system] that works, but sometimes for parents it doesn't work. ... I don't think that they see our point of it.

SP: There's no training for us. I'm trying to figure out my job and trying to do the nurse's job when she's out.

RN: People have lack of respect for school nurses. If you call a physician, they think, "Oh, you're a school nurse." ... I had a mom say, "If you were a real nurse, you'd be working in a hospital. You're not a real nurse."

PCP: We're still butting heads with our patients. We don't understand why they don't take their medicine... "I'm saying it [so] you should do it!"... [but] to be honest I've probably heard more of that inability to understand from school nurses than I have from physicians...

There was also shared uncertainty regarding the role of non-licensed personnel in managing asthma, although reasons for this varied by group. Generally, secretaries were uncomfortable with managing asthma and wanted the nurse to assume responsibility, whereas medication monitors desired greater autonomy and felt devalued by the nurses. In turn, nurses and PCPs vocalized discomfort with non-licensed personnel managing asthma.

SP: It's so bad my teachers bought me a nurse hat. Mondays and Fridays, I put that bad boy on ...so they know that I am doing double duty.... I was never trained, I was just given a job to do.

MM: It's stressful. Why can't we listen to a child who has asthma? We don't have RN behind our name, [but] this is what we hear. We're not diagnosing. It's common sense. [So] I hear a wheeze... I look at [the child] and say, "Do you feel wheezy?" ... Then I put, "Student STATES they feel a wheeze."

S-RN: Our system is faulty...whether you want to admit it or not, you're allowing unlicensed personnel to assess your kids... [MM] have a high school diploma and training provided by us... They get a three-hour degree.

PCP: Don't tell me that anybody's trying to have people who are not RNs take that job. That is a terrible idea....You have to be a nurse.

Minor themes

Lack of knowledge about asthma management and belief barriers as impediments to asthma management were also identified across interviews. Lack of knowledge was more commonly identified by school personnel whereas beliefs barriers were more commonly referenced by families, as exemplified below:

PCP: The previous generation expects kids with asthma [will] be in the emergency room a lot. What's the big deal? Like, that's life with asthma, you know?

SP: Most of us are not trained and have no idea... The only way I know about inhalers, is because I have one...

Administrator: Having zero symptoms... I don't think that that's realistic.

Discussion

This is one of the first studies to qualitatively explore multi-level perspectives of school-based asthma care across the broader asthma care community. Similar to recent reports, our analyses revealed broad support for school-based asthma management.⁴¹⁻⁴³ In addition, our findings highlighted previously unidentified challenges that could be addressed to optimize school-based programs, including a need for greater systemic support for school-based care (i.e. resources, time, and training). Our findings underscore the importance of contextual influences, which can impact broader uptake, efficacy, and long-term sustainability of school-based interventions. We believe addressing these issues will be central to maximizing long-term success.

Prior research has established numerous barriers to asthma management, including poor access to care and attitude and belief barriers.^{16,17,26,27} Our findings support and extend on this by showing how relationship challenges and difficult communication create or amplify barriers and contribute to the overall burden of care at family and systems levels.²⁸ We uncovered examples of discordant relationships between asthma care community members, difficult communication, and distrust of other care community members that could limit individuals' ability to work collaboratively. As one administrator expressed, "*couldn't we just go back to the old days when we could talk?*"

This comment points to issues of communication that lie at the heart of asthma care coordination. We know continuity of care is essential to improving outcomes.²⁹ Implicit within continuity of care is the idea of ongoing, effective communication and continuity of *caring relationships*. Yet, development of caring relationships is contingent upon systems level factors,³⁰ specifically, *time*—the most commonly identified systems barrier in this study. Similar

to other studies, participants (nurses, school personnel, PCPs) reported substantial role-strain arising from insufficient time to deliver asthma care, both at school and in general.^{31,32} This might be partly attributable to value-based healthcare models, which have increased expectations that healthcare personnel "do more with less."^{33,34} Yet, is it possible to manage one or more chronic conditions, address health maintenance tasks, *and* develop therapeutic relationships, all within a single brief office visit?

In short, it is necessary to acknowledge that *both* families and systems are operating in survival mode,³⁵⁻³⁷ and we cannot, like Alice in Wonderland, achieve "six impossible things before breakfast."³⁸ As a care community, we face a difficult reality that has been exacerbated by pandemic-related systems strain.³⁹ In the greater hierarchy of needs, where resources are limited, critical needs (individual/systems) must be met first.⁴⁰ When operating in survival mode, acute issues will always take precedence over routine, preventive asthma care. Substantial improvements in asthma outcomes will require addressing resource-related issues, including ensuring that individuals have enough time to deliver *and* receive asthma care.

Finally, shifting healthcare systems to proactive (versus reactive) asthma care models might help to change family's reactive approaches to asthma management. Systems must first find a way to provide convenient, meaningful (i.e. person-centric) care, with the added challenge of convincing skeptical consumers we are providing something they want. This, once again, requires resources. As succinctly stated by one PCP, we can't "*do it on the cheap—because it doesn't work.*" Thus, our challenge is to find the resources to move beyond a crisis-based systemic approach to asthma management. Quality health care and lack thereof both come at a price. Our choice lies not in *whether* we pay for asthma management—but in *how* we pay—with physical resources, or health, well-being, and human futures.

While having strong face validity, findings from this study should be generalized with caution. First, data were from a population of symptomatic, at-risk children and came from participants located in a single geographic region. Second, child focus groups included broad age ranges, and thus did not elicit developmental differences. Third, use of broadly mixed adult focus groups could have obscured important racial differences in perceptions and experiences. Lastly, our findings differed from the almost exclusively positive feedback about SBC reported anecdotally to program administrators. The lack of congruence might be due to the purpose of this study—which was to identify barriers, challenges, and areas for improvement—but could also be due to participants being less comfortable sharing concerns with program administrators. This latter possibility points to the importance of conducting formal program assessments utilizing independent interviewers, as was the present case.

In conclusion, we believe our findings speak to critical issues in healthcare, specifically, the need to allocate sufficient resources to realistically achieve *proactive* asthma care—including improving communication, access to care, care continuity, and relationships across the care community. As the use of school-based healthcare increases, this might mean having a full-time nurse available at each school and minimizing the use of unlicensed personnel to improve the safety, efficacy, and efficiency of care.

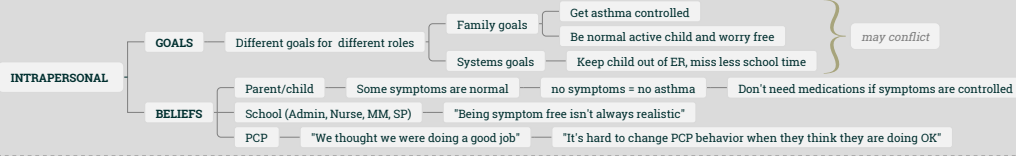
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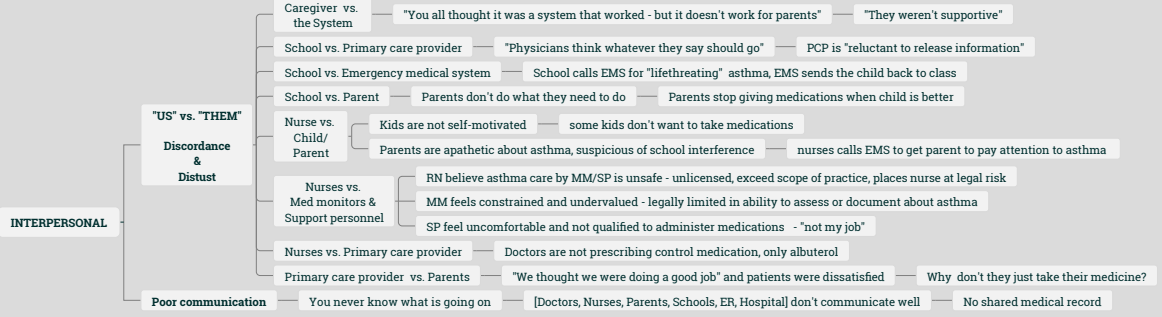
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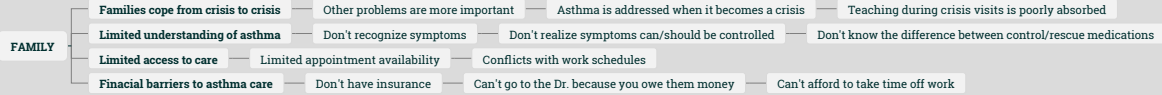
Beliefs about asthma and goals for asthma management are not shared and may be a barrier to child asthma management.



Discordance, distrust, and poor communication across all levels of the asthma care community hinder ability to work collaboratively.



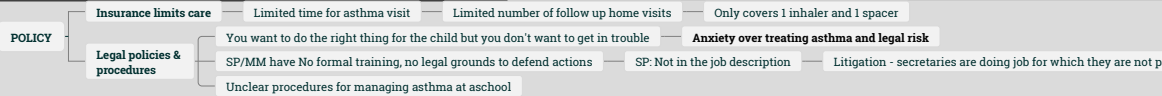
Families operate in crisis mode and asthma management is often not the top priority.



There are insufficient resources to support asthma care (time, money, access to personnel and appointments). Systems operate in crisis mode, focusing on highest acuity issues, and preventive asthma care is not a top priority.



There is insufficient policy level guidance and support for asthma management



MAIN THEMES WITH SUPPORTING CODING SCHEMA

Table 1. Demographic distribution and interview characteristics by participant category

Participant:	Child (N=16)	CG (N=14)	MM (N=7)	SP (N=5)	RN (N=13)	Pharm (N=2)	PCP (N=2)	Admin (N=6)	Payor (N=1)
Focus group (# of groups)	2	2	1	1	2	1	0	2	0
1:1 Interview (# of interviews)	0	0	0	0	1	0	2	2	1
Average Interview duration (minutes)	32 min	77 min	77 min	59 min	79 min	24 min	41 min	43 min	40 min
Age Range	7-17 years	24-68 years	32-56 years	26-62 years	43-62 years	34, 28 years	54,64 years	38-57 years	51 years
Female Sex (%)	38%	100%	100%	100%	100%	50%	50%	86%	0%
Race/ethnicity									
Black (%)	62.5%	57.1%	0%	83.3%	0%	0%	0%	0%	0%
Hispanic/Latino (%)	0%	0%	0%	0%	7.6%	0%	0%	0%	0%
White (%)	37.5%	42.9%	100%	16.7%	92.4%	100%	100%	100%	100%

Notes. *Participant role in child asthma management*: Admin=Administrative (School Principal, Home health administrators; Child= child with asthma; CG=home caregiver of child with asthma; MM=Medication monitor; RN=Nurse (school and home health); PCP=Primary care provider; SP=non-medical school support personnel (secretarial/office staff); Payors=Managed care organization); Pharm=Pharmacist.

Table 2. Primary goals of child asthma management across different participant groups

Participant :	Child	CG	H-RN	MM	SP	S-RN	Pharm	PCP	Admin	Payors
PERSON ORIENTED GOALS										
Live like a "normal" active child – Have no problems with asthma	1 st	1 st				2 nd		1 st	2 nd	
Get asthma controlled – best symptom control possible		1 st					2 nd	2 nd	2 nd	2 nd
Grow out of asthma, be less dependent on medications		1 st							2 nd	
Worry less about child asthma management (due to good control)		1 st				2 nd				
Promote child self-management of asthma		2 nd				1 st			2 nd	
HEALTH CARE AND SCHOOL ORIENTED GOALS										
Minimize emergency care: Keep child out of ER/avoid calling EMS						1 st	1 st	1 st	1 st	1 st
Maximize in school instructional time and reduce missed school days						1 st	2		1 st	2 nd
Have a full time school nurse in every school									1 st	2 nd
Enable families to effectively and consistently manage asthma			1 st	1 st					2 nd	
Improve communication (family, school, PCP, hospital)			1 st						2 nd	
Promote assessment and follow up with the PCP								2 nd	2 nd	
Improve controller medication adherence/ratio of control to rescue medicine				1 st						2 nd

Notes. 1st=primary goal of child asthma management; 2nd= secondary goals of asthma management.

Notes. *Participant role in child asthma management:* Admin=Administrative (School Principal, Home health administrators; Child= child with asthma; CG=home caregiver of child with asthma; H-RN=Home visiting nurse; MM=Medication monitor; RN=Nurse (school, home health); PCP=Primary care provider; Pharm=Pharmacist; Payor=Managed care organization; SP=non-medical school support personnel (secretarial) had no stated goal; S-RN= School nurse.

Table 3. Facilitators of child asthma management – both those actually experienced/observed and hypothetical (proposed) facilitators

Participant :	Child	CG	H-RN	MM	SP	S-RN	Pharm	PCP	Admin	Payor
Facilitators: Experienced/Observed										
SBC improves child asthma management	X	X	X	X		X	X	X	X	X
SBC promotes consistent medication administration routine and refills		X	X	X		X		X	X	
SBC makes managing asthma easier when there is a full-time nurse		X		X		X			X	
SBC means that you don't have to worry as much		X		X		X				
SBC improves relationships and communication between stakeholders				X		X		X	X	X
SBC provides additional resources (time, support, training, finances)				X		X		X	X	X
SBC Medication delivery by mail improves access at school/home			X	X		X		X	X	
SBC Peer support improves asthma management						X				
SBC helps to educate people about asthma				X				X		
SBC reduces emergency care									X	
SBC means less missed class time									X	
SBC home nurse improves child asthma management			X						X	
SBC Dispensing multiple inhalers and spacers improves medication access								X		
Good relationships make managing asthma easier		X	X	X		X		X	X	
Timely/convenient scheduling of appointments improves follow up		X	X			X		X	X	
Incentives for child improves adherence	?			X		X				
Facilitators: Hypothetical (Proposed)										
Improve communication across all levels		X	X	X	X	X	X	X	X	X
Full time school nurse for each school			X	X	X	X	X		X	X
Standard procedures for managing asthma at school		X		X	X	X			X	
Consistent medication routine (right dose, right time)		X		X	X	X			X	
Training for non-medical school staff in asthma and management					X	X				
Consistent method for tracking if child received daily dose at school/home					X					
Reminder system that supports established medication routine					X					
EMR to improve communication school, home, homecare, PCP, ED		X				X	X	X	X	X
Case management to support effective child asthma management						X		X	X	
Parent incentives for keeping follow up healthcare appointments								X		
PCP incentives for better asthma management (outcomes)								X		
Consistent relationships – Seeing same PCP/RN over time		X	X	X		X		X	X	X
Call center to support family questions would help									X	
Telehealth to improve follow up care									X	X

Notes. SBC=School based asthma care. *Participant role in child asthma management:* Admin=Administrative (School Principal, Home health administrators; Child= child with asthma; CG=home caregiver of child with asthma; H-RN=Home visiting nurse; MM=Medication monitor; RN=Nurse (school, home health); PCP=Primary care provider; Pharm=Pharmacist; Payor=Managed care organization; SP=non-medical school support personnel (secretarial/office staff); S-RN= School nurse.

Table 4. Barriers to child asthma management experienced or observed by different participant groups

	Participant:	Child	CG	H-RN	MM	SP	S-RN	Pharm	PCP	Admin	Payor
Personal	Experience anxiety related to managing child's asthma		X		X	X	X			X	
	General job/role strain related to managing child asthma	X	X		X	X	X		X		
	Lack of knowledge at multiple levels hinders optimal asthma management		X	X	X	X	X	X	X	X	X
	SBC: Increased role/job strain related to dealing with child's asthma <i>if no full time RN</i>		X		X	X	X			X	
Inter-personal	"Us" versus "Them": Feeling like you aren't all playing on the same team or working together creates a sense of opposition, anxiety, and distrust	X	X	X	X	X	X	X	X	X	X
	Poor communication across all levels of care		X	X	X	X	X	X	X	X	X
Child	Kids forget to show up/take their medication	X	X	X	X	X	X		X	X	
	Difficult to tell who has asthma – not always clearly communicated									X	
	Difficult to control environment/exposures outside of school		X		X	X	X			X	
Family	Families live from crisis to crisis – asthma management is not top priority		X	X	X	X	X		X	X	
	Beliefs about asthma hinder optimal asthma management	X	X	X	X	X	X		X	X	
	Parents are hard to get ahold of and may not follow up – limits effective care				X	X	X	X	X	X	
	Families have trouble <i>scheduling and attending</i> convenient, timely, meaningful visits (Preventive asthma care: burden > benefit)		X	X			X		X	X	
	SBC: Negative perception of SBC/school interference is obstacle to shared management		X	X	X		X		X	X	
	Cost of medications and healthcare visits is burdensome						X				
Systems	SBC: Inadequate procedures for storing, distributing/dispensing medications				X	X	X	X		X	
	SBC: Insufficient school nurse coverage (RN covers several schools)				X	X	X			X	X
	SBC: Insufficient training for staff in asthma management										
	SBC: Difficult to tell if child is getting medication as intended at home/school		X		X	X	X			X	
	SBC: Limited physical space to manage asthma (storage, assessment, treatment)				X	X	X	X		X	
	PCP: Doctor's visits are scheduled months away, scheduling is difficult										
	PCP: Most children with asthma don't have Rx for control medication					X	X				
	Lack of care continuity, lack of established therapeutic relationships		X	X			X		X	X	
	Medication: Inconsistent or limited access to asthma medication/spacers		X		X	X	X			X	
	Money: limited money to support staff time, training, nurse/staff availability				X	X	X	X		X	
	Time: everyone is too busy – doing more with less time (RN, PCP, SP, Pharm)		X	X	X	X	X	X	X	X	
Legal/Policy	SBC: Significant concern/anxiety over legal risk associated with SBC, confidentiality, scope of practice, non-medical personnel administering medications/managing asthma				X	X	X			X	
	Cannot control child asthma management when not at (home/school)		X		X	X	X			X	
	Insurance often does not cover second or misplaced inhaler		X		X			X	X	X	

Notes. SBC=School based asthma care. *Participant role in child asthma management*: Admin=Administrative (School Principal, Home health administrators; Child= child with asthma; CG=home caregiver of child with asthma; H-RN=Home visiting nurse; MM=Medication monitor; RN=Nurse (school, home health); PCP=Primary care provider; Pharm=Pharmacist; Payor=Managed care organization; SP=non-medical school support personnel (secretarial/office staff); S-RN= School nurse.

Table 5. Lack of structural and policy level support adversely affects child asthma management

Component	Quote
<p><u>TIME</u></p> <p>Inadequate time to perform job related duties competently</p>	<p>SP: The phone’s ringing, the doorbell’s ringing, the parents are looking at me... students need their inhaler, oh my goodness, I’m trying my hardest to time it. ... I’m just like, you all going to have to wait because I’m giving this inhaler. Parents are getting angry because you’re not answering the doorbell.</p> <p>MM: kids coming in the clinic when I'm trying to take care of the asthma kids. I mean, I know we can't be exclusive to asthma for the first half hour of the day, but... It would be nice if teachers could hold the paper cuts and the lost teeth until 8:30....If your arm's falling off, [just] stay in the class.</p> <p>H-RN: School nurses, the phone could be ringing, [an] irate parent, “Why did you send my child home?” [Another] child comes in needing an inhaler. The child [with] diabetes, you calculate insulin. Something happened on the playground! All happening all at once. We are not seeing people one at a time.</p> <p>S-RN: We don’t have time to spend 15 minutes, That school is very busy, [you have to] get the kids in and out within five minutes</p> <p>PCP: physicians have this whole line up of things they need to do at every visit...there could be much greater problems that are more pressing [than asthma]... we have like seven minutes</p> <p>Payor: the nurse or secretary or whoever just feels too busy</p>
<p><u>MONEY</u></p> <p>Limited financial resources to support care</p>	<p>PCP: practices can’t afford the resources [for] a comprehensive asthma program</p> <p>Admin: We want to do it all. [But] We can’t do it all – we have to be very cautious of how we are spending public dollars.</p> <p>MM: Some parents aren't legal...they can't afford the medicine.</p> <p>Payor: Other barriers is getting approval to fill the medications. We’re asking for medications to go to the school, but also to go in a home, and there’s been some issues from a health plan prior authorization process, making sure that we’ve got the approval to get multiple inhalers filled at the same time.</p> <p>Admin: the insurers would not pay for a second spacer, so the spacer stayed home, then they’re not using the spacer with the medication</p>
<p><u>SPACE</u></p> <p>Insufficient storage and operating space</p>	<p>Pharm: it’s just resources and it’s space.</p> <p>Admin: There’s no locked cabinets in the office. We’re lucky there’s a cabinet at all, and honestly like a two-drawer file that locks isn’t a good option. ... there other things in those drawers that other people shouldn’t be getting into? So space [is a problem]</p> <p>SP: I don’t have space.... I’ve got two medicine cabinets. One is nothing but inhalers...but it’s just like my middle shelf is stacked.</p>
<p><u>POLICIES & PROCEDURES</u></p> <p>Unclear roles and operating procedures</p> <p>Insufficient protection against risk</p>	<p>SP: my principal started this – we take all the inhalers in the morning, set them on top of our refrigerator, and that’s how we know who’s left to give</p> <p>RN: Who’s responsible to give the medication? if the [secretaries are] the one doing it they’re gonna have to leave their other job for 20 minutes to do the meds. Okay, if the secretary is doing this, somebody else needs to be the secretary.... [and] there's a problem with understanding scope of practice</p> <p>Payor: The challenge is delivering the medication to the school. [Using] a nurse to deliver meds is inefficient [so] we switched to the pharmacy mailing the meds...they’re struggling getting the medications to a bunch of different schools, to the right person opening the package and knowing what to do with it. Does it go to the home office or does it go to the actual school? Does it go to the actual nurse? How does it go to the patient? So, a lot of logistics.</p> <p>SP: After the incident this past fall, [my husband] was like, " You’re putting us in jeopardy," ...I told him I stopped, but I haven’t</p> <p>MM: I was told that it's no longer considered legal to be working under someone else's license. Only if they're in the room. When I first got the job I was told everything I did went underneath the nurse's license.</p>
<p><u>DATA</u></p> <p>Insufficient data to inform care</p>	<p>Payor: I don’t think you’re going to show me that I’m saving money with this, but if you could show that this had a measurable increase in the number of hours the kids were in class, that would be a big ...you know, for every child in the program, they’re going to be in school an extra six days a year ... that would translate into real money at the school district because they get paid per instructional hour</p> <p>S-RN: [Data] provides support provides support for what we're doing...hard, concrete evidence that nurses make an impact in schools. We're currently trying to get more staff. We've been turned down again but we ask. F: Every year. But, you know, they like data.</p> <p>Pharm: Anything that helps us run reports and track outcomes, I think that that would be good.</p>

Notes. *Participant role in child asthma management:* Admin=Administrative (School Principal, Home health administrators; Child= child with asthma; CG=home caregiver of child with asthma; MM=Medication monitor; RN=Registered Nurse (school, home health); PCP=Primary care provider; Pharm=Pharmacist; Payor=Managed care organization; SP=non-medical school support personnel (secretarial/office staff); S-RN= School nurse.

Table 6. Communication problems between key members of the asthma care community impedes effective child asthma management

Group	Quotes
CG	<ul style="list-style-type: none"> ▪ Having 20 different doctors ... for parents it's frustrating. I don't want to come in here every time my daughter has to go to the doctors and I've got to tell [doctor] this is what happened. ... you've got the chart, why are you asking questions on why I'm bring her in? it's just frustrating. ▪ [The scheduler] says, "Well, you can't see [Doctor] today because [Doctor] doesn't have any openings," but [Doctor] said, "Call on this day to get an appointment because I'm in this office." So either the doctor's lying or Central Scheduling is lying, or maybe they're just lazy...It's like, "Let me rush you off the phone. If you don't want this appointment, we won't schedule. You need to call back and reschedule." I don't have time for all that. ▪ What's that nurse's name? I gave her business up, because her attitude is really nasty. ▪ Asthma's not something that's really talked about per se. It's more swept under the rug.
SP	<ul style="list-style-type: none"> ▪ I am grateful for my nurse because when she is there the communication is [good] and I can talk to her, ask her questions about things. But when she's not... ▪ The nurse does all that paperwork and so she sees that [information]. (General agreement) But we don't see that. ▪ If the teacher takes attendance and doesn't mark them down, we don't even know if they're absent or not. ▪ Parents don't give us good numbers all the time either. (Agreement) They don't keep the numbers updated, so we can't even get a hold of parents. ▪ I didn't even know about this program. I just got stuck. I'm supposed to do the inhalers? I'm like, what? When did this happen? Why are we doing this?
MM	<ul style="list-style-type: none"> ▪ I have a little bit of a communication breakdown. I have Somali. I just wonder how much, like even though if we read it to them and discuss with them the questions, how much they're understanding and their families are truly understanding what that scoring means. ▪ Sometimes the kids give me more information and more reliable information than a parent does. A parent will totally contradict, like...she says, "He's faking it." ▪ F: Parents think the child is doing much better than what the child perceives. They say, "I don't know. They've been at school,"..."I'm at work,"... "I don't know how they sleep," or, "I'm gone before they get up in the mornings, so I don't know." That's hard. The parents are all like, "Oh, no symptoms in the last week or four weeks," and the child still has all these symptoms...
S-RN	<ul style="list-style-type: none"> ▪ Mom took the inhalers with her to go on spring break and she got in the routine of doing it at home with him, so he kept coming in, and said, "I got it at home," so then like verifying that [is hard] and then you can't get a hold of [mom]. ▪ We never hear from the parents... but we hear the kids tell us that they were in hospital..."You were? What were you there for?" "I don't remember." ▪ [Parents] sign the form ... that gives us permission to talk to the physicians, [but] you won't accept it at [Hospital] ▪ I sent like the third consent form over [to the hospital], and they still claim they don't have it, so... [Hospital] is on my crap list right now.
H-RN	<ul style="list-style-type: none"> ▪ Sometimes we don't get a positive response because we are communicating non-verbally a whole bunch of negative things to these families. I have found that families are very skilled at picking up non-verbal communication...if you believe that they don't care about their children, it's going to be communicated.
Pharm	<ul style="list-style-type: none"> ▪ We need better integrated communication among all of the players in the SBC program, so there's more efficient ways of sharing information.
PCP	<ul style="list-style-type: none"> ▪ We have no idea how many times they're calling the squad. We have no idea how many times they're not going to school [because of] asthma. We have no idea how many times they're sitting out from recess. we rely on good chart communication between the school and the hospital. ▪ If you don't have a provider that's a person that you relate to, you're done...It's about relationship....it's about communication. We've lost that because we're too big. One mom said [to me], "I'm never coming back here again." I was like, "Really?" She says, "No. I'm going to have a real doctor," and I was like, "Oh, what do you mean?" and she's like, "You know, a real doctor like every time I go there I'll see the [same] doctor." We're not that people.
Admin	<ul style="list-style-type: none"> ▪ There's this communication barrier. They don't give us information. Physicians are reluctant to give us a lot of information...and some of that is parents not wanting the school to have all this information.... couldn't we just go back to the old days where we could just talk? ▪ Getting information from families. That's the biggest [problem]. Does the child have asthma? Getting the information schools need to manage the child in school, the medication, the asthma action plan, ongoing communication if they have an exacerbation, if they've increased using their inhaler, those kinds of things.
Payor	<ul style="list-style-type: none"> ▪ Everyone is assigned a primary care physician. They may not have a relationship, but they all have one assigned to them.

Notes. *Participant role in child asthma management:* Admin=Administrative (School Principal, Home health administrators); Child= child with asthma; CG=home caregiver of child with asthma; MM=Medication monitor; RN=Registered Nurse (school, home health); PCP=Primary care provider; Pharm=Pharmacist; Payor=Managed care organization; SP=non-medical school support personnel (secretarial/office staff); S-RN= School nurse.

Table 7. Discordance between asthma care community members impedes collaborative child asthma management

Group	Quotes
<p><u>CG</u> vs. "System"</p>	<ul style="list-style-type: none"> ▪ You all feel like it's a [system] that works, but sometimes for parents it doesn't work. ... I don't think that they see our point of it. It's frustrating. ▪ My son was like, "They told me I don't need it [medication]." What? Who said that? I'm coming down there like, "Why aren't you giving his medicine?" ▪ We couldn't get [an inhaler] because of health insurance. They weren't supportive...[and] I was scared to send him to school with no inhaler
<p><u>Admin</u> vs. CG, EMS, and PCP</p>	<ul style="list-style-type: none"> ▪ This kid now belongs to you <i>and</i> the parents, ... And if mom's not coming, you've got to take [the child to the ED] because the parents say, "I'm not coming!" ▪ When we call the squad [EMS], and especially when a nurse calls, it's for a <i>life-threatening situation</i>. Squad comes in, and they'll give a treatment and say, "They're fine. Stay in school." [but] ...I don't trust all of our paramedics and EMTs to know what they're doing. What if [the child] had a slight improvement and [they] then rebound and the teacher doesn't identify [it]?...We don't like dead children at school. ▪ Physicians are reluctant to give us information... they think that whatever they say should go. It's like, yeah, they can come back to school. Really?
<p><u>MM</u> vs. RN and School</p>	<ul style="list-style-type: none"> ▪ Some staff want to tell us how to do our job. They tell us, "This child needs their inhaler," when they aren't the med minder. They hear the child making a cough, but overall it's up to us and our nurse. Some teachers that feel they know more than I do. ▪ One child I felt like I really needed to listen...so I notated [did] and then my nurse wasn't happy with me doing that because I don't have RN behind my name. ▪ My nurse says, if we ever called a witness stand and they looked at you [they'll say] are you a nurse? My nurse has me paranoid now...
<p><u>SP</u> vs School and CG</p>	<ul style="list-style-type: none"> ▪ It falls on the secretaries. And really it's not in our job description. Our union is very upset with this situation. Because we're not compensated for it or anything. We're not asked if we want to do it. We're told to do it. Pretty much with no training, so me, I am very uncomfortable with that ▪ I'm the only secretary there and Wednesdays and Fridays our nurse isn't there, and parents want to come pick up early, people buzzing the doorbell, so if I forget to call [the child] to get her inhaler... how does that look on me because I forgot, but at the same time I have my other business that I have to do as well. ▪ You never know who's going to pop in and audit you. This is what we have also in the back of minds—If we don't stay on top of this, it is going to [be] us ▪ I'm trying to figure out my own job and then trying to do the nurse's job when she's out, with no training.... making a mistake is not something we can do ▪ That's my question... mom, dad, these are your kids. Why aren't you taking the initiative to give this to this kid at home? Love them, don't you? ▪ I just don't trust it. ... a parent can always say we did something, or didn't do something, And how do we back ourselves up, because we've not been trained? ▪ This kid can't breathe...we want to call the [EMS] squad, [but]...If [parents] have signed 'do not transport', the squad can come, give a treatment, but they can't take them because the parents already refused - they don't want the bill.... [I] suppose you're going to let [the child] die on the premises.
<p><u>Nurses</u> vs. CG, SP, MM, Teachers, and PCP</p>	<ul style="list-style-type: none"> ▪ There's certain families that just won't comply, and that's really frustrating because the kids are the ones that are suffering. ▪ It's the frustration of the parents. They just seem to be nonchalant about asthma. I've had parents tell me, "That's normal for him." That drives me crazy. ▪ When you have people covering for you, they're documenting in the wrong area and I have to figure out... ▪ I've had a teacher refuse to let her student come down to get an inhaler...and I told the teacher that's not appropriate ▪ It's the staff in the office...when the secretary goes to lunch you have to have [other] people trained, so it's those people that are resistant. ▪ Med monitors are doing school nurse jobs, but they don't have the education. ... I would get rid of the MM position. [We need] LPNs and RNs in every school. ▪ The primary care doctor...they just keep giving them the albuterol or the course of steroids and don't put them on a controller. ▪ [Med monitors] pass themselves off as the nurse. Then you're calling, spending ten minutes, "I promise you I'm the nurse. I really am the nurse." ▪ We can't trust our translator...[he] doesn't really translate. He says what he wants to say. We'll spend 10 minutes explaining and he'll spend 15 seconds. ▪ If you think this [poorly] about our vulnerable populations...maybe you should think about another group of people you want to work with.... ▪ You [providers] think that people are non-compliant, like 'they're not doing what I say' instead of having this partnership
<p><u>PCP</u> vs. CG, healthcare system</p>	<ul style="list-style-type: none"> ▪ I had a patient, the mom was frustrated because we weren't doing anything for the child's cough but she smoked... ▪ We're getting better but we're still butting heads with our patients. We don't understand why they don't take their medicine..."I'm saying it [so] you should do it!"... [but] to be honest I've probably heard more of that inability to understand from school nurses than I have from physicians... ▪ Central Scheduling is not interested in continuity [of care], which is a huge [issue]. So, I'm just being really honest...continuity of care is a disaster here.

Notes. *Participant role in child asthma management*: Admin=Administrative (School Principal, Home health administrators); Child= child with asthma; CG=home caregiver of child with asthma; MM=Medication monitor; RN=Registered Nurse (school, home health); PCP=Primary care provider; Pharm=Pharmacist; Payor=Managed care organization; SP=non-medical school support personnel (secretarial/office staff); S-RN= School nurse.

eSupplement A

Interview Guide for Children

1. What do you think asthma (breathing problem) is? [Asthma illness representations]
2. Who helps you with your asthma?
3. How do you and whoever takes care of you at home take care of your asthma? [Asthma illness representations]
4. Tell me how your asthma medication works? [Asthma illness representations]
 - a. Do you take medication every day for your asthma and what color is it [PROMPT: Do you use something like this?]? [Asthma illness representations]
 - b. How do you know when you need your medications? [Asthma illness representations]
 - c. What worries, if any, do you have about your puffer or inhaler? [Asthma illness representations]
5. Do you ever get scared or worried about your asthma?
6. What is it like for you to have asthma? [Quality of life]
 - a. Does your asthma make you feel different? [Quality of life]
7. What are your goals for your asthma management? [Preferences]
8. What is more annoying to you: having to take medications every day or feeling sick because of your asthma? [Risk tolerance; Time preference]
9. What things make it difficult for you to take care of your asthma? [Budget constraints; Barriers]
10. What is it like for you when you're feeling good? [Quality of life]
11. Do you think you need your asthma medications when you feel good? [Asthma illness representations]
12. What could we do to help you better deal with having asthma? [Needs]

Interview Guide for Caregivers

1. What do you think asthma is? [Asthma illness representations]
2. Who or what could help you better manage your child's asthma?

3. Tell me a little about your morning routine?
4. What is it like for your family and friends to have a child with asthma? [Quality of life]
5. How do you treat your child's asthma? [Asthma illness representations]
 - a. How does the medication work? [Asthma illness representations]
 - b. How often does your child use his/her controller and rescue medications? [Asthma illness representations]
 - c. How do you know when your child needs his/her medications? [Asthma illness representations]
 - d. What worries, if any, do you have about your child's asthma medications? [Asthma illness representations]
6. Do you worry about your child's asthma all the time or only when they have symptoms (e.g., coughing, wheezing, tight chest, shortness of breath)? [Asthma illness representations]
 - a. What do you do when you are worried about your child's asthma? [Asthma illness representations]
7. What are your goals for your child's asthma management? [Preferences]
8. What is more important to you: that your child has no symptoms or that your child doesn't need their asthma medications every day? [Risk tolerance; Time preference]
9. Do you think your child needs to see the doctor or nurse for their asthma even when they are well?
10. What makes you decide to go to the Emergency Room? [Preferences]
11. What things make it hard for you to take care of your child's asthma? [Budget constraints; Barriers]

Interview Guide for School Nurses/Medical Monitors

1. What are your goals for optimally managing children's asthma in your school? [Preferences]
2. Would you rather have scheduled medication administration or have children in your office more often for emergency rescue inhaler use? [Risk tolerance; Time preference]
3. What things make it difficult for you to take care of your students with asthma? [Budget constraints; Barriers]
4. When and why do you call the squad?

5. What services and/or resources would help you better manage asthma for the children in your school? [Needs]
6. For those not implementing the school-based program: Are you aware of the school-based asthma management program?
 - a. What are some of the barriers to not enrolling children in your school(s) in the program? [Barriers]
7. For those implementing the school-based program: What could we do differently to make the program better or get more schools to adopt the program? [Needs]
8. From your perspective, what would it take to get more kids enrolled in the school-based asthma management program in your school(s)? [Needs]

Interview Guide for Home Case Managers

1. What are your goals for optimally managing children's asthma in your caseload? [Preferences]
2. What is more important to you: that the child has no symptoms or that you are able to avoid an ED visit or hospitalization? [Risk tolerance; Time preference]
3. What things make it difficult for you to implement a home case management protocol? [Budget constraints; Barriers]
4. What services and/or resources would help you better manage asthma for the children in your caseload? [Needs]
5. From your perspective, what would it take to implement a home case management program for all [XXX] children with asthma? [Needs]
- 6.

Interview Guide for School Administrators

1. What are your goals for optimally managing children's asthma in your school? [Preferences]
2. What is more important to you: that the child has no symptoms or that you are able to avoid a squad run to the school? [Risk tolerance; Time preference]
3. What things make it difficult for you to take care of your students with asthma? [Budget constraints; Barriers]
4. What services and/or resources would help you better manage asthma for the children in your school? [Needs]
5. What would it take to get the school-based asthma management program implemented district-wide? [Needs]

Interview Guide for Healthcare Providers

1. What are your goals for optimally managing children's asthma in your clinic? [Preferences]
2. What things make it difficult for you to take care of your patients with asthma? [Budget constraints; Barriers]

3. What services and/or resources would help you better manage asthma for the children in your clinic? [Needs]
4. What would it take for you to refer children to the school-based asthma program? [Needs]

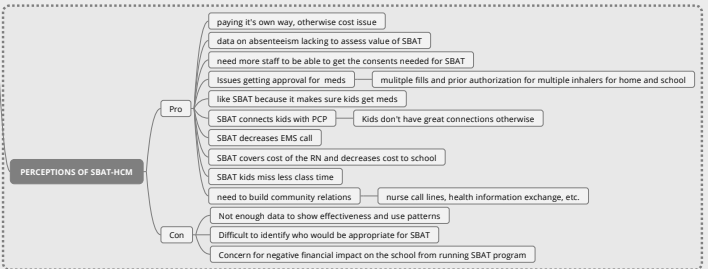
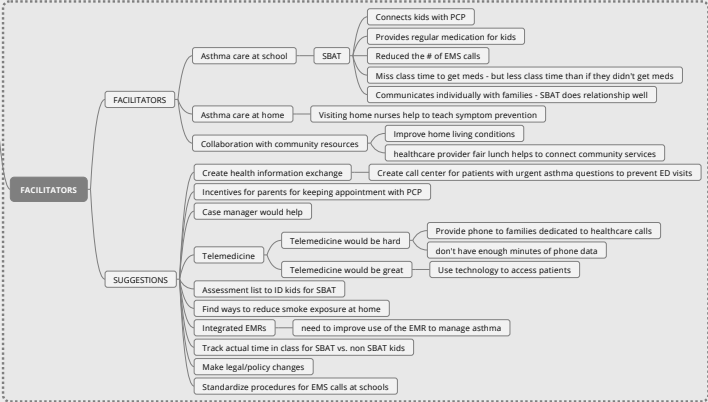
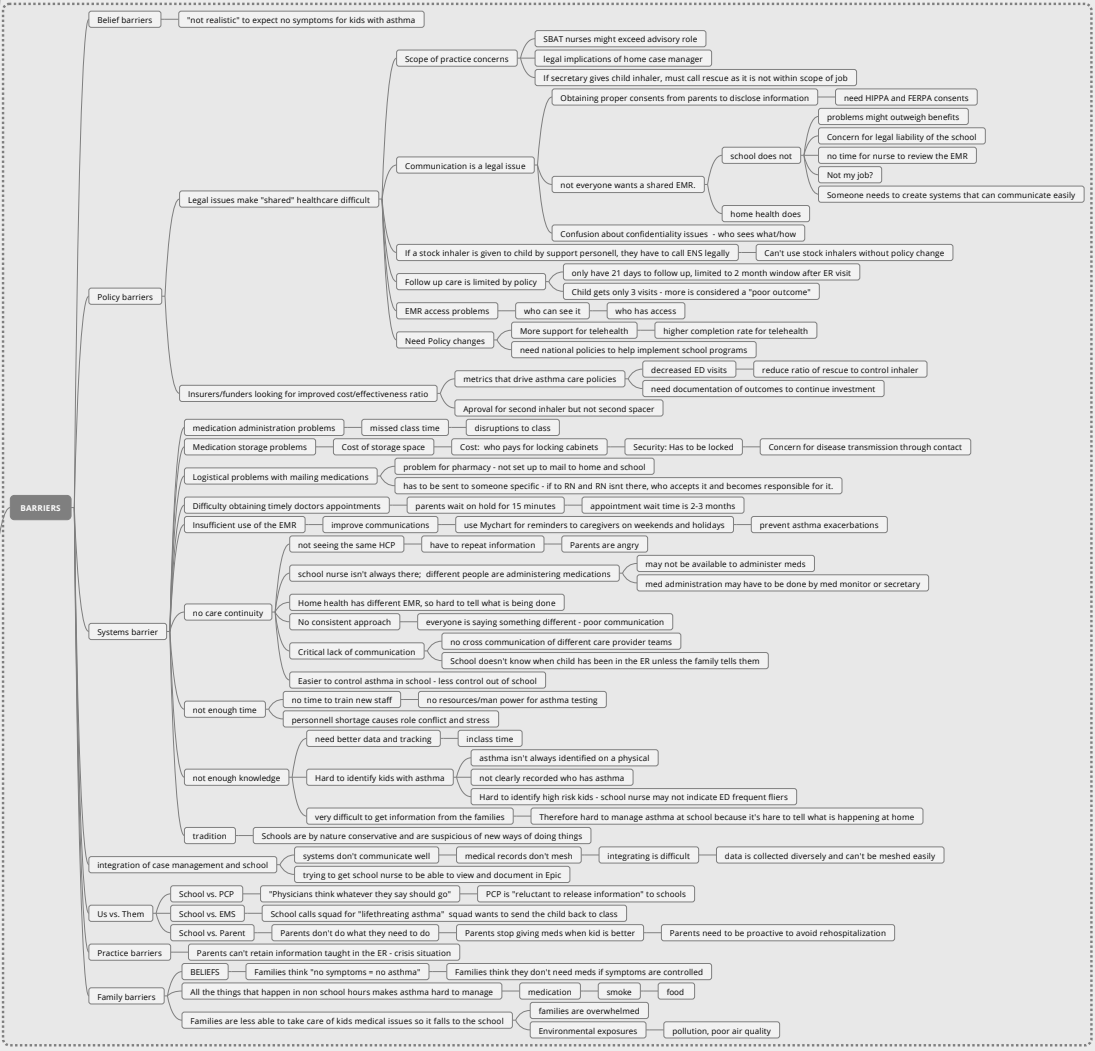
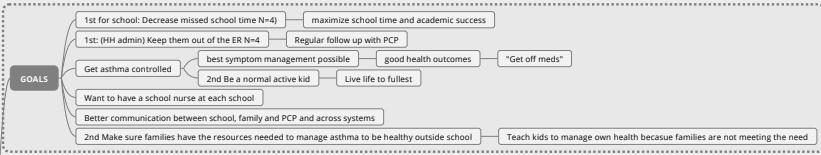
Interview Guide for the Payer

1. What are your goals for asthma management and outcomes for Partners For Kids (XXX)-enrolled children? [Preferences]
2. What things make it difficult to achieve those goals? [Budget constraints; Barriers]
3. What is more important to you: that the child's asthma is under good control or that the child has fewer ED visits or hospitalizations? [Risk tolerance; Time preference]
4. What would it take for XXX to reinvest in the school-based asthma program? [Needs]

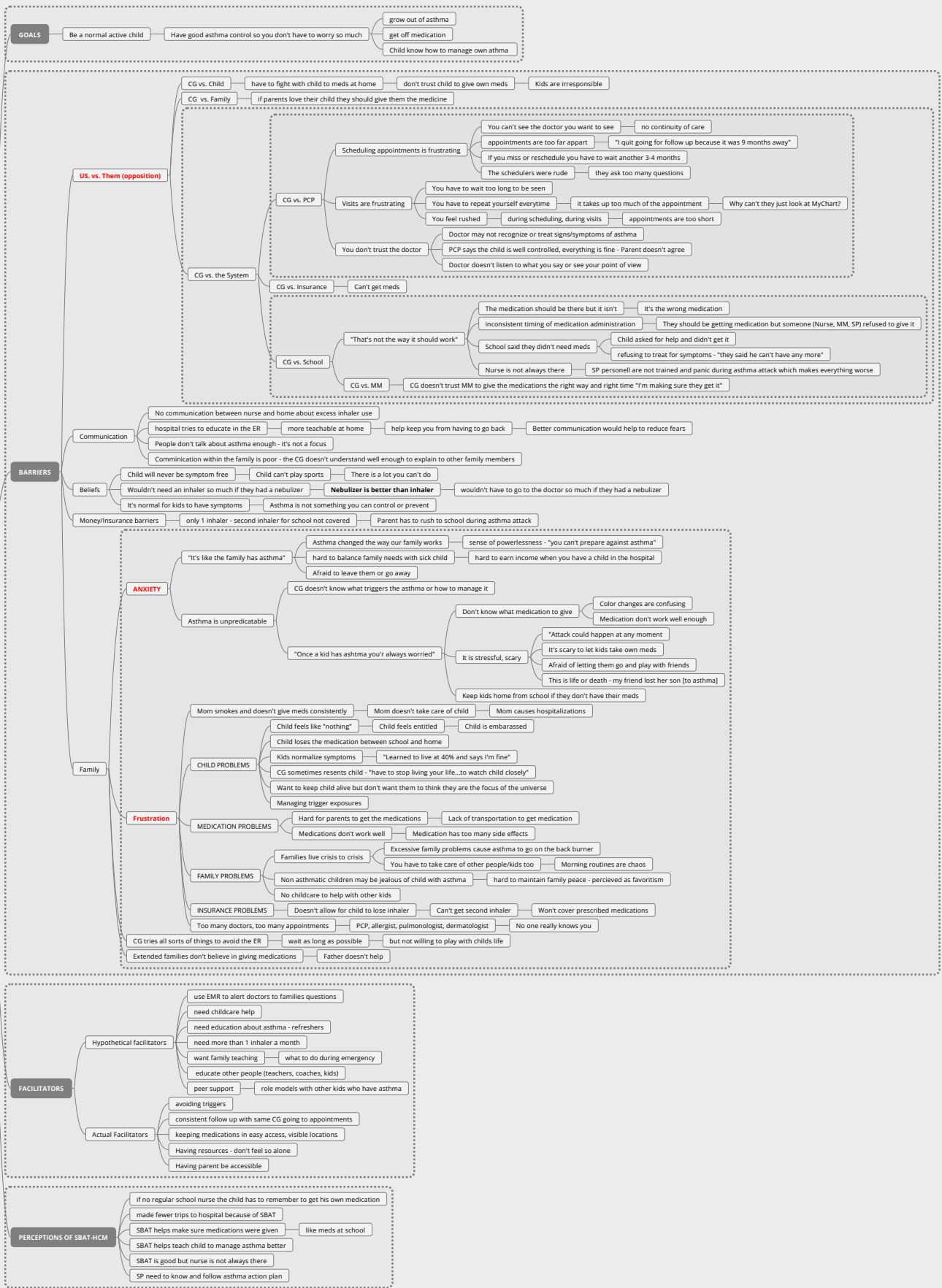
Interview Guide for the Pharmacy

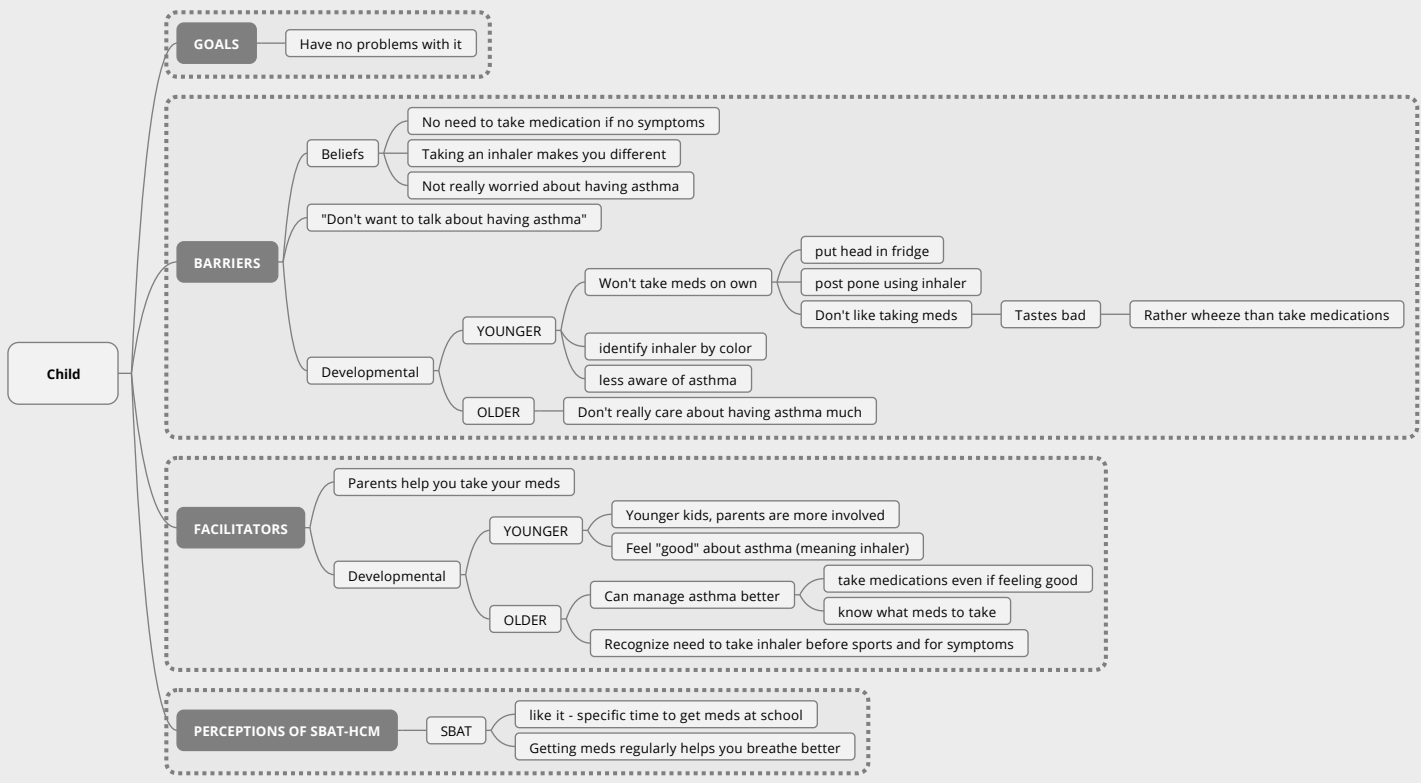
1. What are your goals for the outpatient pharmacy regarding asthma management of XXX-enrolled children? [Preferences]
2. From the pharmacy perspective, what makes it difficult to achieve these goals? [Budget constraints; Barriers]
3. What services and/or resources would help you achieve your goals for these children? [Needs]
4. What would it take for the outpatient pharmacy to be able to scale up the school-based asthma program to accommodate all XXX-enrolled children with asthma? [Needs]

Administrators
School,
Home health Admin
School nurse Association



Caregivers (CG)





GOALS - Have no problems with it

BARRIERS

- Beliefs
 - No need to take medication if no symptoms
 - Taking an inhaler makes you different
 - Not really worried about having asthma
- "Don't want to talk about having asthma"
- Developmental
 - YOUNGER
 - Won't take meds on own
 - put head in fridge
 - post pone using inhaler
 - Don't like taking meds → Tastes bad → Rather wheeze than take medications
 - identify inhaler by color
 - less aware of asthma
 - OLDER
 - Don't really care about having asthma much

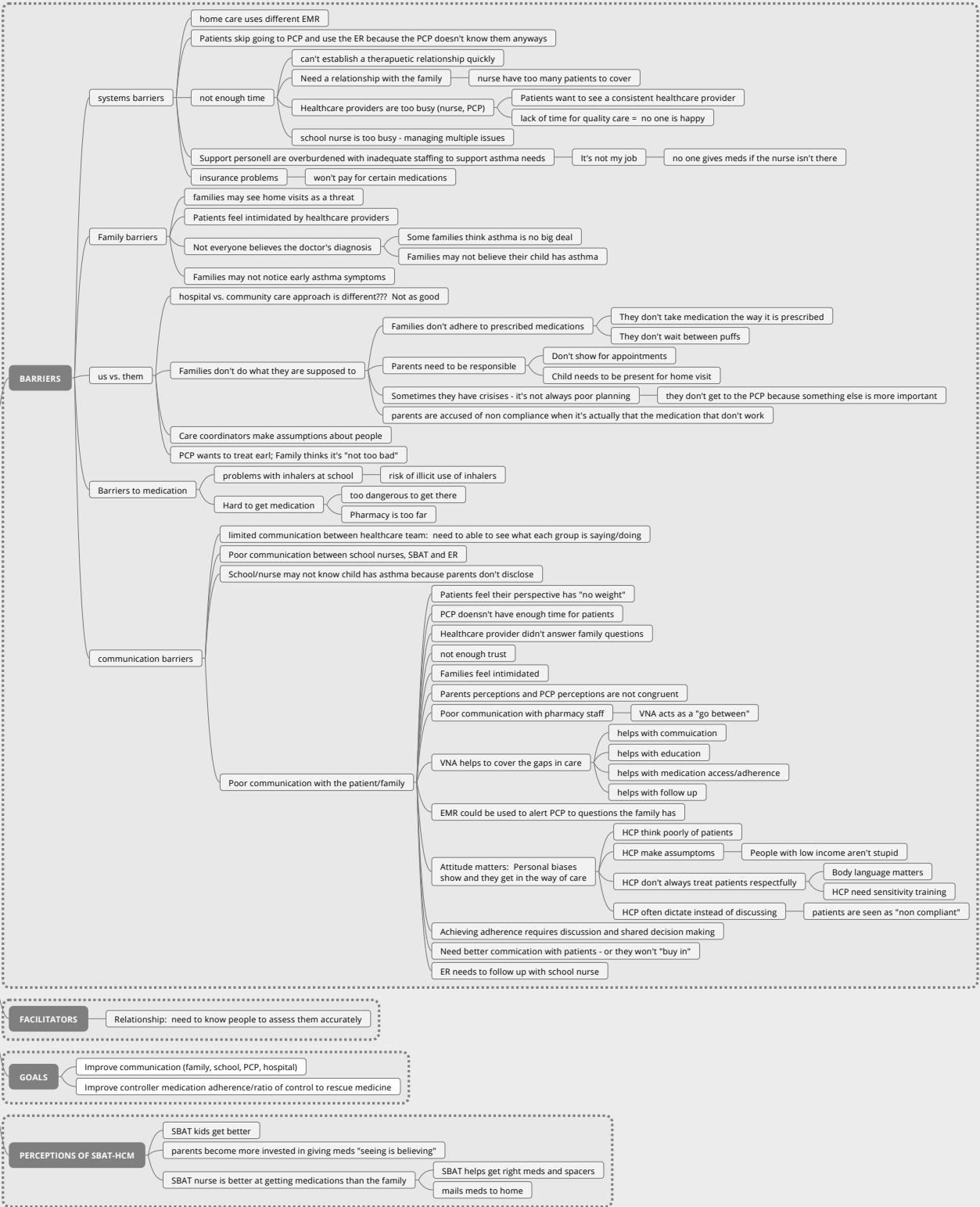
FACILITATORS

- Parents help you take your meds
- Developmental
 - YOUNGER
 - Younger kids, parents are more involved
 - Feel "good" about asthma (meaning inhaler)
 - OLDER
 - Can manage asthma better
 - take medications even if feeling good
 - know what meds to take
 - Recognize need to take inhaler before sports and for symptoms

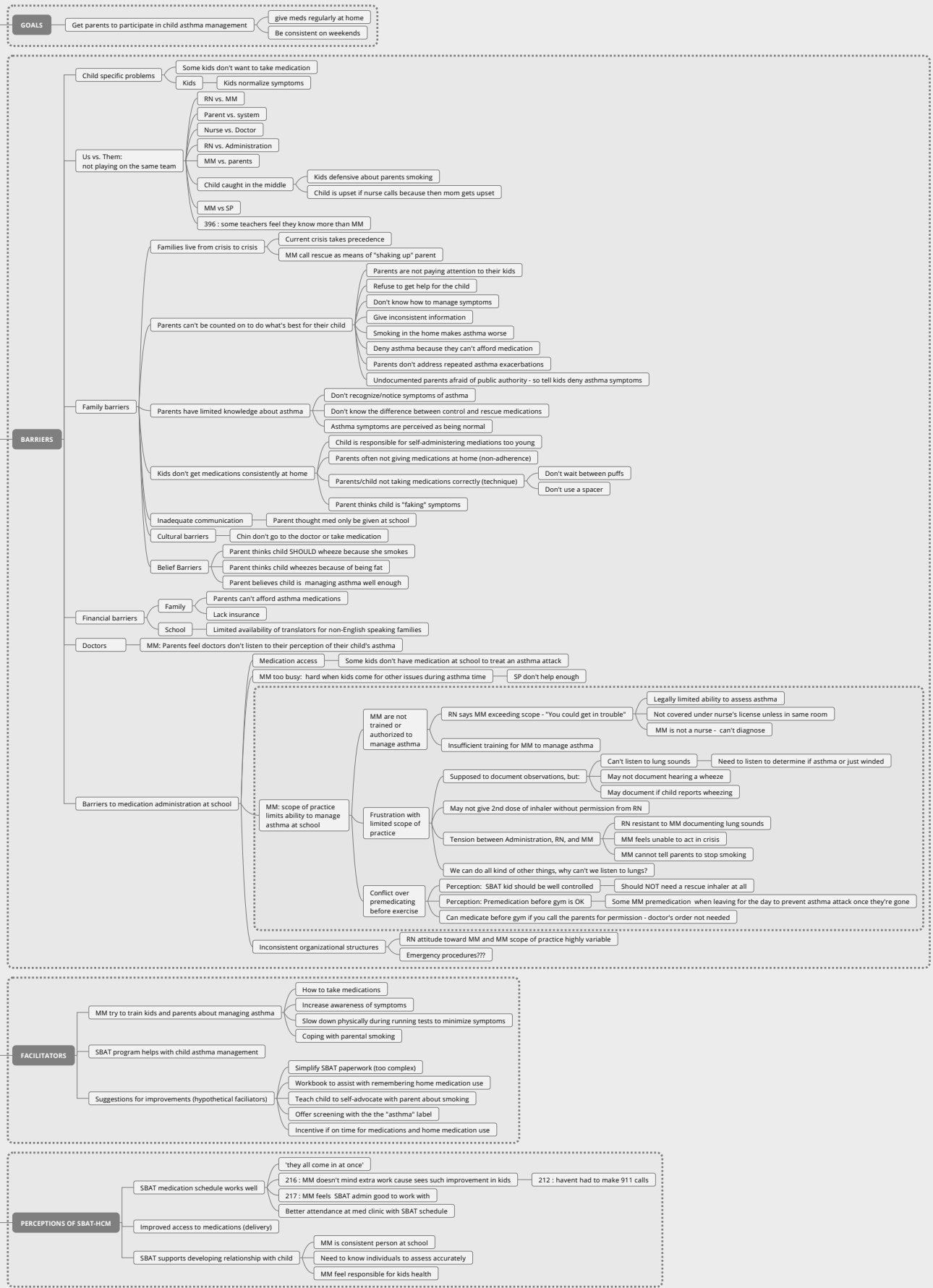
PERCEPTIONS OF SBAT-HCM

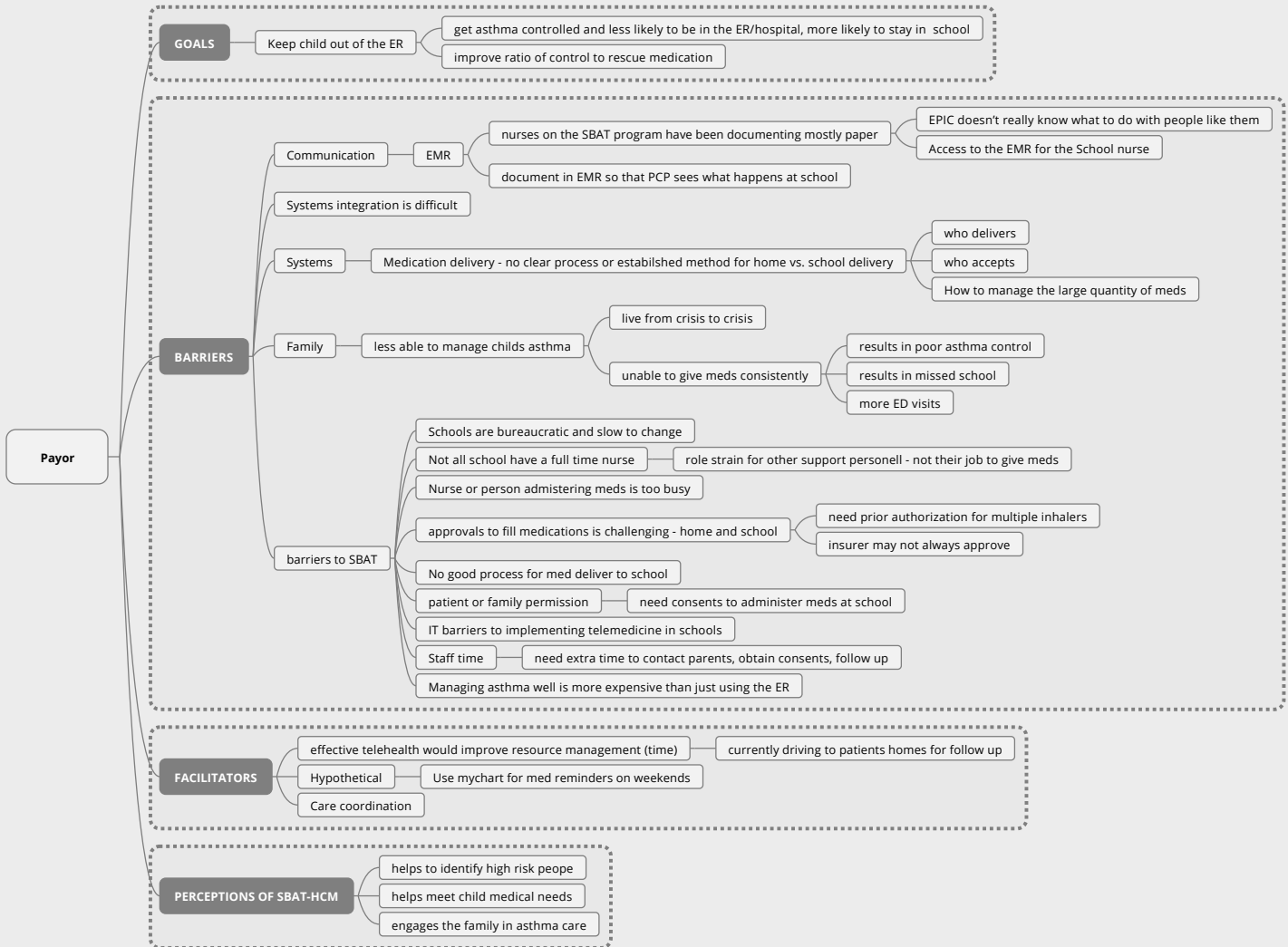
- SBAT
 - like it - specific time to get meds at school
 - Getting meds regularly helps you breathe better

Visiting home nurse



Medication Monitors (MM)





Payor

GOALS

Keep child out of the ER

- get asthma controlled and less likely to be in the ER/hospital, more likely to stay in school
- improve ratio of control to rescue medication

BARRIERS

- Communication
 - EMR
 - nurses on the SBAT program have been documenting mostly paper
 - EPIC doesn't really know what to do with people like them
 - Access to the EMR for the School nurse
 - document in EMR so that PCP sees what happens at school
 - Systems integration is difficult
- Systems
 - Medication delivery - no clear process or established method for home vs. school delivery
 - who delivers
 - who accepts
 - How to manage the large quantity of meds
- Family
 - less able to manage child's asthma
 - live from crisis to crisis
 - unable to give meds consistently
 - results in poor asthma control
 - results in missed school
 - more ED visits
- barriers to SBAT
 - Schools are bureaucratic and slow to change
 - Not all schools have a full-time nurse
 - role strain for other support personnel - not their job to give meds
 - Nurse or person administering meds is too busy
 - approvals to fill medications is challenging - home and school
 - need prior authorization for multiple inhalers
 - insurer may not always approve
 - No good process for med delivery to school
 - patient or family permission
 - need consents to administer meds at school
 - IT barriers to implementing telemedicine in schools
 - Staff time
 - need extra time to contact parents, obtain consents, follow up
 - Managing asthma well is more expensive than just using the ER

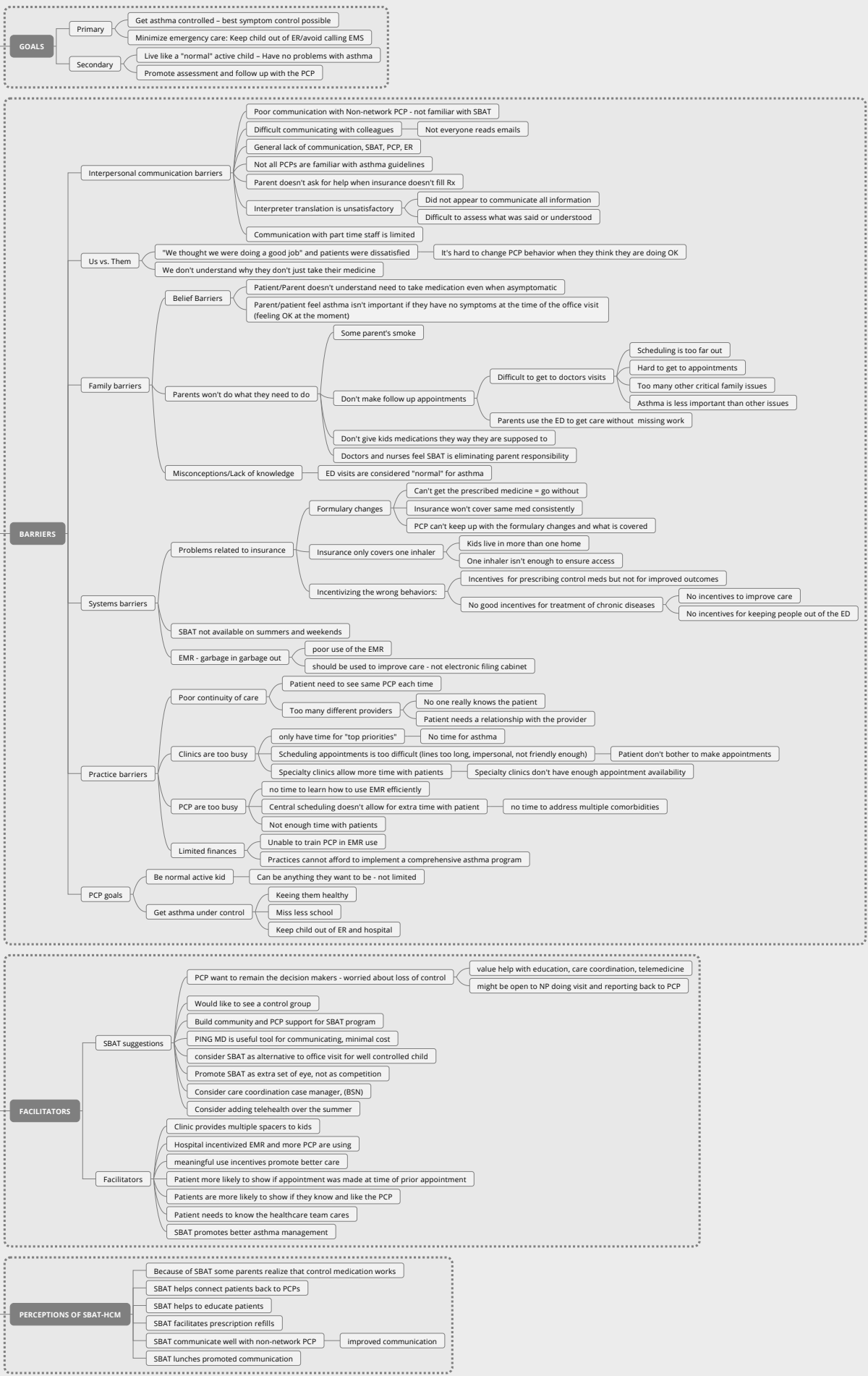
FACILITATORS

- effective telehealth would improve resource management (time)
 - currently driving to patients' homes for follow up
- Hypothetical
 - Use MyChart for med reminders on weekends
- Care coordination

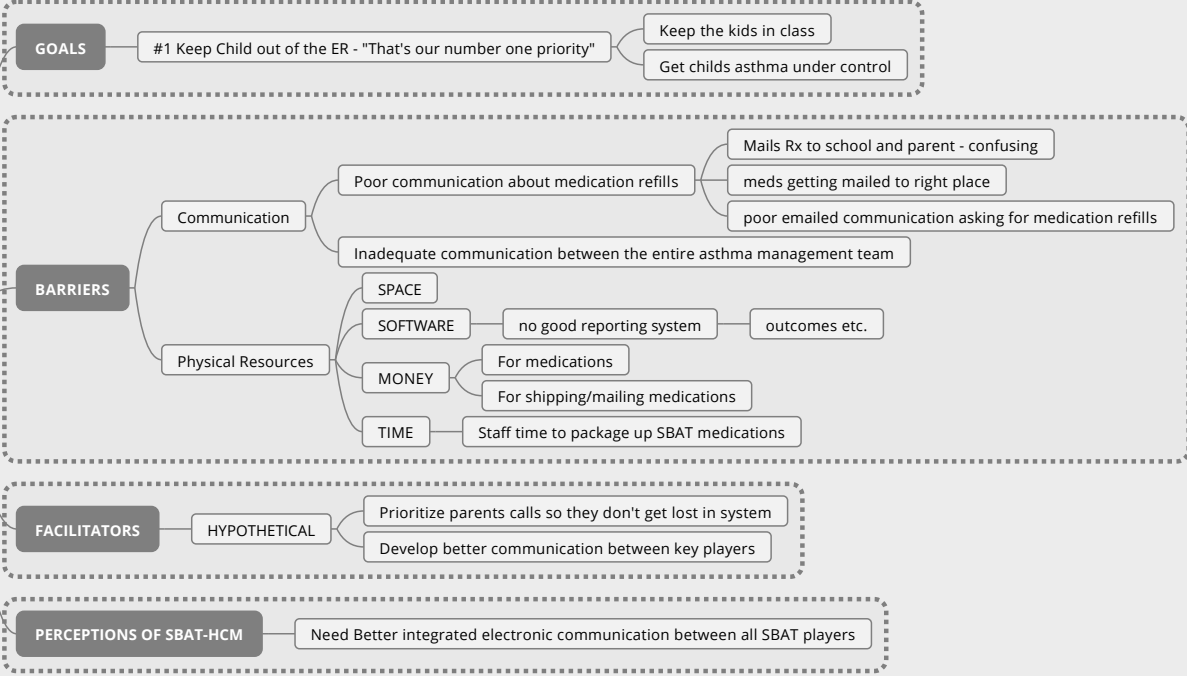
PERCEPTIONS OF SBAT-HCM

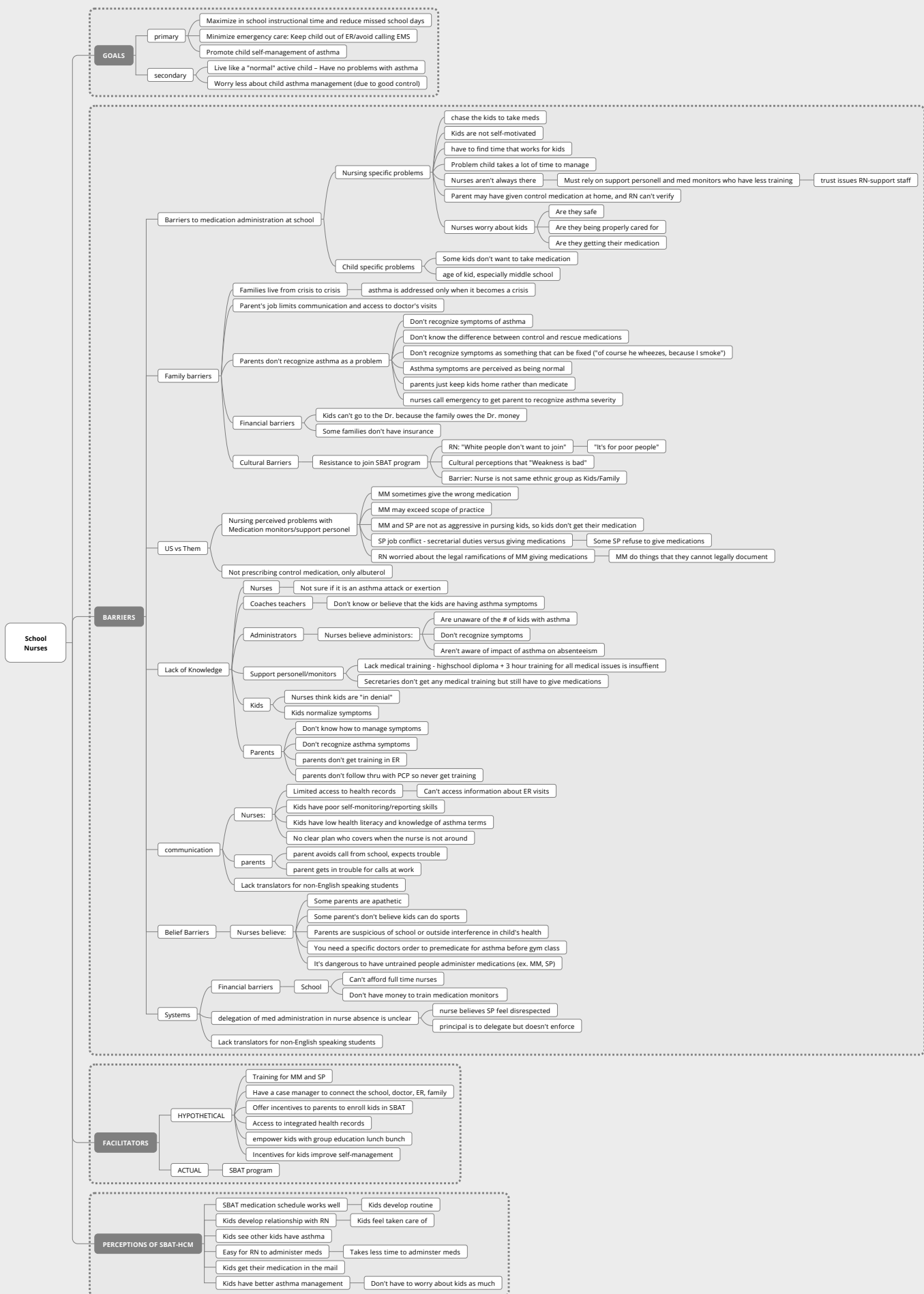
- helps to identify high-risk people
- helps meet child medical needs
- engages the family in asthma care

Primary Care Providers (PCP)



Pharmacist





Secretaries (Support personnel)

