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To cite this article: Carolyn M. Arnold, Paul J. Bixenstine, Tina L. Cheng & Megan M. Tschudy (2018): Concordance among children, caregivers, and clinicians on barriers to controller medication use, Journal of Asthma, DOI: [10.1080/02770903.2018.1424188](https://doi.org/10.1080/02770903.2018.1424188)

To link to this article: <https://doi.org/10.1080/02770903.2018.1424188>



Published online: 08 Feb 2018.



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Concordance among children, caregivers, and clinicians on barriers to controller medication use

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ABSTRACT

Objective: While much research has addressed asthma medication adherence, few have combined quantitative and qualitative data, and none has addressed the triad of child, caregiver, and clinician simultaneously. This study assessed, with mixed methods, barriers to medication adherence within this triad. **Methods:** We conducted interviews with publicly-insured children with asthma, their caregivers, and their primary-care clinicians. Children (7–17 years) had been prescribed daily inhaled corticosteroids and visited the ED for asthma (past year). Participants answered open-ended and survey questions, rating suggested barriers to medication use (never vs. ever a barrier). McNemar's tests compared report of barriers by each group (children, caregivers, clinicians), and assessed concordance within triads. **Results:** Fifty child–caregiver dyads participated (34 clinicians). Children (40% female; median age 10 years) had mostly non-Hispanic black (90%) caregivers with less than or equal to high-school education (68%). For barriers, children and clinicians were more likely than caregivers to report medications running out. Clinicians were also more likely to cite controllers being a “pain to take” (vs. children) and forgetfulness (vs. caregivers) (all $p < .05$). There was a lack of within-triad concordance regarding barriers to adherence, especially regarding medication running out, worrying about taking a daily medication, and medication being a pain to take. Qualitative data revealed themes of competing priorities, home routines, and division of responsibility as prominent contributors to medication adherence. **Conclusions:** There was significant disagreement among children, caregivers, and clinicians regarding barriers to daily use of asthma medications. To tailor asthma management conversations, clinicians should understand family-specific barriers and child–caregiver disagreements.

ARTICLE HISTORY

Received 7 August 2017
Revised 27 December 2017
Accepted 1 January 2018

KEYWORDS

Medication adherence; community pediatrics; mixed methods; family–clinician discordance; cross-sectional design

Abbreviation and acronyms

ACT	asthma control test
AMR	asthma medication ratio
CI	confidence interval
ED	Emergency Department
EHR	electronic health record
IQR	interquartile range
MCO	managed care organization

Introduction

Up to 60% of children with persistent asthma do not maintain their prescribed regimen of a daily anti-inflammatory (“controller”) medication (1–4). This high prevalence of non-adherence has been consistently linked to frequent asthma exacerbations and use of emergency care (5,6). This problem is especially notable

among low-income and black children, who are not only significantly more likely to have asthma, but also more likely to utilize acute care for asthma and to suffer asthma-related morbidity and mortality (7,8). When prescribed controller medications, both pharmacy data (9,10) and self-report (11) show medication underutilization (12).

Prior quantitative and qualitative studies have attributed non-adherence to a variety of social factors (13–16), illness and medication beliefs (17–20), and provider influences (21–23). While this collection of research has contributed to our understanding of the range of barriers to controller medication use, it chiefly relies on individual perspectives in isolation. Few studies have drawn comparisons among the different responsible parties in pediatric asthma primary care, and to our knowledge none have simultaneously addressed at once all three perspectives commonly present in the primary-care exam room: child, caregiver, and clinician. In addition to drawing comparisons between groups (i.e., “children,” “caregivers,” and “clinicians,” broadly), an idea emerging in pediatric research is that the fact that

disagreement exists at all—like caregiver–medical-record concordance regarding treatment (24), or child–clinician concordance on engagement during asthma visits (25)—is itself an important variable. Highlighting the potential consequences of concordance, parent–parent concordance on home nutrition practices has been associated with healthier child eating habits (26), and parent–child concordance on youth violence has been associated with a greater need for mental health services (27). Applied to pediatric asthma medication adherence, a corresponding hypothesis is that a lack of concordance among those involved in asthma medication adherence may be disruptive enough to affect rates of medication use (28). With this in mind, we considered whether there was concordance within a triad (child, caregiver, clinician) regarding barriers to medication adherence. This paper describes rates of concordance, but does not assess whether level of concordance was related to reported medication use.

The objective of this study was to assess differences among child, caregiver, and clinician views toward asthma controller medication barriers, in a predominantly black, inner-city sample of children with poorly controlled asthma. Using a mixed-method, cross-sectional survey, we identified disagreement among children, caregivers, and clinicians in primary care asthma management. Quantitatively, we characterized these differences among the groups as a whole (children, caregivers, and clinicians) and within the triad (measures of “concordance”). Qualitative data elaborated on the nature of these barriers in each family’s experience of asthma medication management. The integration of quantitative and qualitative data allowed for a more nuanced look at each perspective within the triad and suggested additional points of intervention for future study of medication adherence.

Methods

Participants

Participants in this study included “triad” units of a child with asthma, the child’s caregiver, and the child’s primary care clinician. A Medicaid managed care organization (MCO) identified children aged 7–17 years who received care at one of two hospital-affiliated pediatric clinics in Baltimore, MD, and who met the following inclusion criteria: carried an asthma diagnosis, had visited the emergency department (ED) for an asthma exacerbation March 2013–May 2014, and were prescribed a daily inhaled corticosteroid at the time of the visit. Exclusion criteria included developmental delay (as documented in the chart), school difficulty (held back more than one grade in school), history of ventilator dependence or tracheostomy, and significant comorbidity such as other

chronic lung disease, sickle cell disease, or HIV infection. Eligibility was determined initially by the Medicaid MCO and confirmed by chart review.

Procedures

Data were collected through interviews with both quantitative and qualitative elements. Eligible families were first mailed an informational flyer inviting the child and caregiver to participate in an interview, with interviews then conducted either in person following scheduled clinic visits or via telephone. Informed consent was obtained from adult caregivers, and children assented verbally to participation. For a given family, the child and primary caregiver responded to the same interview questions separately (in person or via telephone). Their pediatric clinician, who consented through participation, completed an online survey about the participating child–caregiver dyad, with questions corresponding to those in the family interviews. Children, caregivers, and clinicians received gift cards for participation.

Interviews were within 12 months of the child’s ED visit for asthma. Interviews with children under 12 followed a simplified version of the age 12 and up script. After both child and caregiver had completed interviews, the child’s primary care pediatric clinician—resident, attending, fellow, or nurse practitioner—received an email version of the survey with patient identifiers (name and medical record number) to prompt review of the patient’s recent asthma visits. To maximize clinician participation, we attempted follow-up twice. Clinicians in some cases cared for multiple patient-participants; in these cases, they completed a separate survey for each child.

The semi-structured interview guide was developed based on a clinical needs assessment and literature review and was adjusted (shortened in length, and language clarified for understanding) based on pilot feedback from 5 child–caregiver dyads. Three researchers, one of whom was a native Spanish speaker, were trained to conduct interviews. Children and caregivers had the option to interview in English or Spanish. The study procedures were approved by the Johns Hopkins Medicine Institutional Review Board.

Quantitative data

Survey items

Children, caregivers, and clinicians each rated the frequency with which suggested barriers to medication use applied to the child (5-point scale of “never,” “sometimes,” “often,” “almost always,” “always”). Children responded from their own perspective, and caregivers and clinicians were asked what they believed applied to the child. All 3 parties were provided the same list of suggested

barriers. These barriers were adapted from prior studies on controller medication adherence (29–32): medication runs out, forget to take medication (hereafter “forgetfulness”), don’t think they need medication, worry about taking a medication every day, don’t want to admit they have asthma, too much of a pain to take medication, embarrassed to take medication, and friends say not to take medication. Responses were manually recorded and entered in an electronic database. Demographic information was collected at the close of the interview, including gender, race/ethnicity, language, caregiver marital status, caregiver education, and clinician role (pediatric resident, fellow, attending physician, or nurse practitioner).

To define daily asthma control and medication adherence in the study population, the child and caregiver completed the Asthma Control Test (ACT), which is scored with 5–24 points, where <19 is considered poorly controlled and ≥ 19 adequately controlled (33,34). Child, caregiver, and clinician reported the child’s estimated number of missed controller doses in a typical week, which was trichotomized to a 3-point gradation based on the distribution of responses: “never misses a dose,” “misses 1–2 doses per week,” and “misses ≥ 3 or more doses per week.” Pharmacy data were provided by the insurer and converted to an “asthma medication ratio” (AMR), or the ratio of controller fills to rescue-plus-controller fills. An ideal AMR is considered ≥ 0.5 (35–37). All references to “medication adherence” in the study refer only to daily inhaled corticosteroids (“controller medications”), not to any rescue inhalers prescribed for acute exacerbations.

Statistical analyses

Each suggested barrier to medication use was dichotomized from the reported 5-point Likert scale of frequency to “never a barrier” vs. “ever a barrier” (included sometimes, often, almost always, or always a barrier), which followed the distribution of responses. For each suggested barrier to medication use, it was determined whether there was child–caregiver, child–clinician, and caregiver–clinician concordance (or lack thereof). McNemar’s tests compared proportions of children, caregivers, and clinicians who reported the various barriers to controller medication use (38). Pairwise comparisons (child vs. caregiver, child vs. clinician, and caregiver vs. clinician), not three-way, were made due to lower clinician response rates. The analyses were performed with Stata I/C 13.1 (StataCorp, LLC, College Station, TX).

Qualitative data

Qualitative questions

In addition to identifying suggested barriers to daily controller medication use, participants also responded to

open-ended questions about barriers to and facilitators of controller medication use (Appendix A). Participants answered open-ended questions first, so that they were not primed with the list of “suggested barriers” described above. Interviewers followed a semi-structured guide for open-ended questions, asking follow-up questions where indicated. These responses were audio recorded, then professionally transcribed and translated to English if applicable.

Qualitative analysis

Two interviewers created and iteratively edited a qualitative coding manual while coding the initial interviews. Disagreements in coding were resolved by consensus involving a third reviewer. Twenty percent of the responses were double-coded and tested for inter-rater reliability. After inter-rater reliability was established, the remaining 80% of responses had a single coder. We utilized ATLAS.ti 7 (Scientific Software Development GmbH, Berlin, Germany) to code interviews. Coding and analysis of interviews followed an inductive approach, in which analysts created a codebook only after reading and interpreting a subset of interviews, rather than defining themes a priori (39). The same group of researchers both coded interviews and analyzed quantitative data, so the development of the qualitative codebook may have been influenced by the experience of analyzing quantitative data. These qualitative findings were then triangulated with quantitative data in the interpretation stage, allowing for exploration of convergence, dissonance, and complementarity between quantitative and qualitative data (40).

Results

Participant demographic & health characteristics

The Medicaid MCO generated a list of 920 children they deemed appropriate for participation; however, after 2 authors manually reviewed the electronic health records, only 88 children were indeed eligible according to inclusion criteria. Most children ($n = 773$) were ineligible due to lack of ED visit for an asthma exacerbation; in many cases, asthma was listed as a diagnosis but not the primary reason for the ED visit. Of the 88 eligible children, 50 child–caregiver dyads participated (57% response rate), with 34 of the 50 corresponding clinician surveys completed by 26 unique clinicians (68% response rate) (Figure 1).

Children (40% female; median age 10 years, interquartile range (IQR) 6.5) had mostly non-Hispanic black (90%) caregivers with a high-school education or less (68%). The majority (92%) of the caregivers surveyed were the child’s birth parent, and most clinicians surveyed

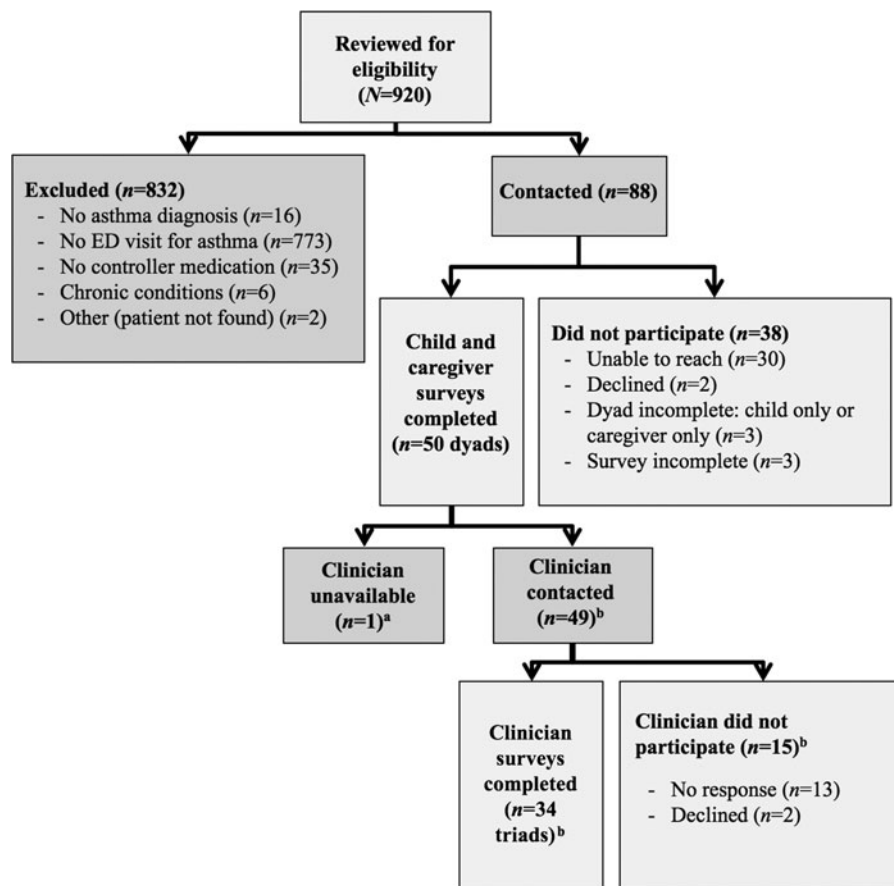


Figure 1. Study overview. ^aClinician graduated/left clinic during study. ^bClinician values in this figure refer to numbers of clinician surveys (not clinicians as individuals), with one for each child. If a clinician cared for multiple children who participated, they completed a survey for each child participant.

(71%) were pediatric residents. One child–caregiver dyad participated in Spanish (Table 1).

Surveyed children averaged 1.38 (SD 0.99) ED visits and 0.48 (SD 0.58) admissions for asthma in the past 12 months. Scores on the ACT averaged 14 (SD 4.4) as reported by children and 18 (SD 4.6) as reported by caregivers, indicating poor control overall. Children (58%) and caregivers (48%) most commonly reported that the child missed only 1–2 doses of controller medication per week. At the same time, pharmacy records indicated that the majority (60%) have less than ideal adherence, with AMR <0.5.

Quantitative findings: Barriers to medication use

Comparison of children, caregivers, and clinicians

Every barrier inquired about in the survey was endorsed at some point, but among all 3 groups surveyed, forgetfulness (82% children, 80% caregivers, 100% clinicians) and medications running out (65% children, 44% caregivers, 94% clinicians) were the most frequently mentioned barriers to medication use (Table 2). Other commonly reported barriers included children not

thinking they need the daily medication (49% children, 40% caregivers, 58% clinicians) and children being worried about side effects (43% children). Although less commonly reported overall, notable proportions of children said that they avoided using the controller medication because they were afraid to admit they have asthma (27%) or because they were embarrassed to take the medication (16%).

There were significant differences among child, caregiver, and clinician report of these barriers. Children were more likely than caregivers ($p < 0.001$) to report medications running out as a reason for non-adherence, and clinicians were more likely than both other groups ($p = 0.03$ vs. children, $p < .001$ vs. caregivers) to report medications running out as a barrier. Clinicians were more likely than children to cite controllers being a “pain to take” ($p = 0.002$) and more likely than caregivers to cite forgetfulness as a barrier ($p = .03$).

Concordance within family dyads and triads

Examining concordance within triads (Table 3), there was high within-dyad and within-triad concordance in reporting that forgetfulness was a barrier and in

Table 1. Sociodemographic and health characteristics of children, caregivers, and clinicians.

Children (N = 50)	
Age (Median [IQR] year)	10 (6.5)
Gender (n [%] male)	30 (60%)
Race (n [%] black)	45 (95%)
Language (n [%])	
English	49 (98%)
Spanish	1 (2%)
ED visits past 12 months (mean [SD])	1.38 (± 0.99)
Admissions past 12 months (mean [SD])	0.48 (± 0.58)
Asthma control test	
Child-reported score (mean [SD])	14.0 (± 4.4)
Caregiver-reported score (mean [SD])	18.2 (± 4.6)
Missed controller doses/week (n [%])	
Child report of 1–2 miss/week	29 (58%)
Child report of 3+ miss/week	10 (20%)
Caregiver report of 1–2 miss/week	24 (48%)
Caregiver report of 3+ miss/week	8 (16%)
AMR ^a (n [%] < 0.5)	30 (60%)
Caregivers (N = 50)	
Gender (n [%] female)	41 (82%)
Role (n [%] birth parent)	46 (92%)
Marital status (n [%])	
Single	36 (72%)
Married	9 (18%)
Divorced, separated, widowed	3 (6%)
Other, decline	2 (4%)
Education, (n [%])	
< High school	13 (26%)
High school graduate/GED	21 (42%)
> High school	16 (32%)
Race (n [%] black)	45 (90%)
Ethnicity (n [%] non-Hispanic)	46 (92%)
Language (n [%] English)	49 (98%)
Clinicians (N = 26)^b	
Gender (n [%] female)	23 (89%)
Role (n [%])	
Resident physician	21 (81%)
Fellow (physician)	1 (4%)
Attending physician	2 (8%)
Nurse practitioner	2 (8%)
Race (n [%] white)	17 (65%)
Ethnicity (n [%] non-Hispanic)	22 (85%)

^aAMR: Asthma medication ratio (equivalent to the ratio of controller fills to rescue-plus-controller fills), where AMR < 0.5 represents less than ideal medication adherence.

^bDemographics presented for 26 individual clinicians, who completed a total of 34 clinician surveys, as presented in Figure 1.

reporting that friends telling the child not to take the medications was rarely a barrier to use. The lowest overall concordance (21% of triads) was regarding whether medication being too much of a pain to take was a barrier, and there was a similar lack of concordance (only 27% of triads concordant) regarding whether the child worried about taking a medication every day. On a dyad level, child-clinician dyads differed most in whether they thought worrying about taking a medication every day was a barrier. Interestingly, child-clinician dyads had high rates concordance regarding medications running out (79% of dyads), whereas child-caregiver and caregiver-clinician dyads were less frequently concordant (57% and 47% of dyads, respectively).

Qualitative findings: Barriers to medication use

In response to the question, “What makes it difficult to take the controller medication every day?” participants often cited the same barriers we later proposed in closed-ended questions. As an example, in concordance with the question about embarrassment, one child (male, 12 years) said, “When I’m outside I don’t want to use it that much ‘cause—it’s not embarrassing, but it seems like it is.” Other times, as follows and as presented in Table 4, new themes emerged, illustrating some of the drivers behind medication non-adherence: competing priorities for both child and caregiver, difficulties related to routines at home, as well as conflict over the division of responsibility for the medication. While there was often concordance among children, caregivers, and clinicians as to the broad themes of medication barriers, there was a lack of concordance over who is ultimately responsible.

Competing priorities

When children discussed forgetfulness, they typically attached it to “competing priorities” of daily childhood activities such as outdoor play or school work. For caregivers, the competing priorities included conflicts between work hours and controller dose timing, as well as balancing competing needs of other children or older relatives. These priorities prevent caregivers from being physically present for the medication administration in some cases, and from making their usual reminder phone call in other cases.

Home structure and routines

Children made it apparent that their forgetfulness was often linked to a lack of structure or routine in taking the medication in their household. They often used the word “rush,” which seemed to indicate that there was not a specific time or space carved out in morning routines for medication adherence. Caregivers were not in concordance with this notion, but several caregivers echoed the overall importance of the home structure, bringing up the idea that their medication routines are frequently disrupted by the child spending time in multiple homes.

Division of responsibility for medication

The division of responsibility for taking the daily controller medication was a prominent feature, particularly for caregivers and clinicians. While children rarely “blamed” anyone else, a substantial number of caregivers deferred the responsibility away from themselves and spoke instead about the child’s forgetfulness and preoccupation with other activities. With respect to responsibility, clinicians added that a lack of caregiver supervision or an inappropriate level of responsibility given to young children were also barriers. Clinicians backed up this view of inappropriate responsibility with

Table 2. Proportion of children, caregivers, and clinicians reporting barriers to the child's daily controller medication use.

Barriers to medication use	Report of barriers to medication use, by group*			McNemar's test for correlated proportions		
	n (%)			p-value		
	Children N = 50	Caregivers N = 50	Clinicians N = 34	Children vs. caregivers	Children vs. clinicians	Caregivers vs. clinicians
Medication runs out	32 (65)	22 (44)	29 (94)	0.03	0.03	<.01
Forget to take medication	41 (82)	40 (80)	31 (100)	1.00	0.06	0.03
Don't think they need medication	24 (49)	20 (40)	18 (58)	0.50	0.46	0.21
Worry about taking a medication every day	21 (43)	13 (26)	7 (23)	0.13	0.17	1.00
Don't want to admit they have asthma	13 (27)	7 (14)	2 (6)	0.21	0.06	0.69
Too much of a pain to take medication	12 (24)	13 (26)	19 (61)	1.00	<.01	0.08
Embarrassed to take medication	8 (16)	2 (4)	6 (19)	0.11	0.63	0.29
Friends tell not to take medication	3 (6)	1 (2)	2 (7)	0.63	1.00	0.50

*"Report of barrier" includes saying barrier applies to that child "sometimes," "often," "almost always," or "always," and not "never." Statistically significant results (at level $p < 0.05$) bolded.

the notion that young children had an incomplete understanding of the purpose of the controller medication when asymptomatic.

Discussion

Despite much research on pediatric asthma management, including exploration of barriers to controller medication use, rates of controller medication adherence remain low, particularly in urban and low-income areas (3,4,15). This study adds a mixed-methods approach, as well as the triad perspectives of child, caregiver, and clinician. Our findings suggest that children, caregivers, and clinicians differ in how they perceive barriers to daily asthma medication use. Both children and clinicians were more likely than caregivers, for example, to say that medications running out were a barrier, and clinicians were more likely to say that daily medication was a "pain" to take.

These results from a sample of low-income children with poorly controlled asthma reaffirm the importance of several barriers previously known to be predictors of non-adherence. In particular, family report of forgetfulness, the child perceiving no need for medication, and worry about daily medication use were all reported as barriers to medication use (1,14,15,18). This study adds qualitative data, though, and suggests that forgetfulness was frequently linked to household context, evident in child comments about "rushing" and caregiver comments about routine disruptions (e.g., other caregivers). Although the relationship between these comments and level of adherence was not assessed here, these qualitative findings align well with prior studies linking better adherence to families with more highly rated organization and "function" in the household, meaning they rely more heavily on routines, the perceived burden of those routines is not onerous, and the parents report good behavioral control in children (15,16,41).

Table 3. Proportion of dyads and triads that are concordant in their report of whether each barrier applies to that child. "Concordant dyads" are defined as both individuals reporting either "ever a barrier" or "never a barrier." In a "concordant triad," all 3 individuals agree.

Suggested barriers to medication use	Concordant [^] Dyads n (%)			Concordant [^] Triads n (%)
	Child–caregiver (N = 50)	Child–clinician (N = 34)	Caregiver–clinician (N = 34)	Child–caregiver–clinician (N = 34)
Medication runs out	28 (57)*	26 (79) [†]	16 (47)	14 (39) [†]
Forget to take medication	43 (86)	29 (85)	24 (82)	26 (76)
Don't think they need medication	30 (59)	18 (51)	18 (53)	13 (36)
Worry about taking medication every day	27 (55)*	14 (42) [†]	20 (59)	10 (27) [†]
Don't want to admit they have asthma	33 (67)*	28 (85) [†]	27 (79)	23 (67) [†]
Too much of a pain to take medication	26 (53)*	18 (54) [†]	11 (32)	8 (21) [†]
Embarrassed to take medication	39 (80)*	29 (88) [†]	25 (73)	25 (73) [†]
Friends tell not to take medication	41 (92)*	31 (97) [†]	32 (94)	31 (91) [†]

[^]Concordance meant the 2 (dyad) or 3 (triad) groups agreed about whether or not the suggested barrier applied to the child, *N = 49, [†]N = 33, due to incomplete child survey.

Table 4. Summary of relevant themes that emerged from qualitative data, along with sample quotes to illustrate, regarding barriers to daily medication use.

Themes and sub-themes	Sample quotes
Competing priorities	
– Child's other activities	"Sometimes, I forget, like things come up ... like basketball games, football games, stuff like that." (male, 13 years) "Even though it's only going to take like 10, 20 seconds, it's just me worrying about what's going on or am I going to miss something or will I miss out on something." (male, 12 years)
– Caregiver's job(s)	"So like we open in the restaurant at 6:00, so that's when she is getting up and getting ready for school most, so I can't really get to her to really tell her all the time." (mother of female, 7 years)
– Responsibility for other family members	"I have a four-year-old that I'm running after, a six-year-old that I'm running after, so I'm trying – we're actually trying to teach her to be more responsibility for herself. She's about to be 11. She's in the third grade." (mother of female, 10 years)
Home structure and medication routines	
– Lack of time built in for medication	"Well we be – we be late to school. My momma be in a rush to try and get us to school. When we be going somewhere, we might be in a rush and I might forget to take my medicines." (male, 10 years)
– Multiple homes	"Well, half the time he'll be with me but when he is with me, I give him his medicine. His grandfather forgets to give him his medicine." (mother of male, 10 years)
Division of responsibility for medication	
– Defer responsibility to other party	"Basically him just being a kid, wanting to just go outside and play and that's the last thing on his mind." (father of male, 9 years) "If he don't take it it's because he just forgot or we wasn't on top of it." (father of male, 17 years)
– Perceived inappropriate division of roles	"[The] patient [is] required to manage medication without supervision." (clinician, regarding male, 9 years)
– Too young to understand "preventive" medication	"[It is] difficult to take a medication twice per day, every day, when it does not alter how your body feels immediately after taking it." (clinician, regarding female, 9 years)

Qualitative themes also revealed that the division of responsibility for the medication plays a role. In their comments about medication barriers, caregivers tended to defer responsibility to the child, making note of child forgetfulness or unwillingness. Meanwhile, children seemed to assume responsibility in their discussion of medication barriers, usually blaming themselves and not others. Clinicians, though, said that caregivers were not taking a big enough role in medication use. Taken together, these themes bring into question appropriate distribution of medication responsibility between child and caregiver. Prior studies cite negotiation of this responsibility as a prominent part of asthma management and have found that children assume up to

50% of medication responsibility by age 11 (42,43). Thus, clinician probing of the division of responsibility between child and caregiver may provide a good starting point for addressing adherence.

Antecedent studies have generated the hypothesis that there may be differences in perceived barriers to daily medication use among children and caregivers, with little mention of clinicians' perception of barriers (44,45). This study showed that clinicians tended to overemphasize the role of medications running out and being a pain to take, when compared to child and caregiver reports. Rather than implying clinicians do not understand barriers to asthma medication use, these findings likely suggest limits in clinician knowledge of individual family barriers, something they at times identified themselves and something not surprising in a high-turnover resident clinic. While clinicians rightly assessed that forgetfulness was an important barrier overall, this study shows that there is often a more nuanced explanation to that "forgetfulness." Carpenter et al. (2014) showed that children are not frequently engaged in their asthma visits at the level they desire (25). Our results suggest that through such improved engagement of children, clinicians may gain better knowledge of the individual patient's situation and more effectively address medication adherence barriers in that family.

Our results surrounding non-concordant opinions within the triad further underscore the need for clear communication in pediatric encounters surrounding barriers to medication use. Reports show that clinicians bring up the topic of medication adherence in fewer than half of regular asthma visits (23,46,47), that caregivers are unlikely to discuss adherence unless explicitly asked (21), and that caregivers are often left with misunderstandings at the end of medication conversations (19). The many differences in barriers endorsed by child, caregiver, and pediatric clinician show the need for conversations with all 3 parties about barriers to medication administration. This may be especially true in clinics where continuity is a challenge, as these results are drawn from a majority-resident-clinician sample. It may be helpful for the clinician to facilitate a conversation between child and caregiver about that particular family's difficulties. Clinicians should pay attention to those child-caregiver pairs that disagree about barriers, with the hypothesis that a lack of concordance alone may be enough to derail daily adherence, though this deserves more study.

Several factors limit the generalizability of our findings. As this is a cross-sectional study, we cannot identify causal relationships. Involvement of clinicians to form a triad of perspectives was a novel approach, but clinician involvement introduced several limitations: They had a very low response rate, they completed a different format survey to accommodate their schedules, and a single

clinician was permitted to complete multiple surveys for each patient participant. Moreover, we did not control for clinician type (i.e., resident vs. nurse practitioner), and individuals with different levels of experience and different lengths of relationships with patients may have responded differently.

This mixed-methods study assesses root causes of child asthma medication non-adherence and suggests the need for care that is tailored to individual families' barriers. Next steps for improving medication management might include expansion of asthma education programs for children and caregivers (23,48) or school-based medication management to lessen the burden of home asthma routines. Within the clinic, primary care clinicians may also benefit from practical and efficient communication tools, such as shared-decision making tools (49,50) or prompts built into electronic health records to assess responsibility for medications, to support families appropriately.

Conclusion

Children, caregivers, and clinicians report different barriers to daily inhaled corticosteroid use for persistent asthma, and while clinicians appear to understand general barriers to medication adherence, they often lack insight into the barriers of individual patient families. In our low-income population, medication barriers included lack of a daily routine and overreliance on the child taking responsibility for medication administration. High rates of disagreement among children, caregiver, and providers about barriers to medication adherence highlight the need for communication within families and with providers about medication use barriers and tailored strategies.

Acknowledgements

Thank you to the families and clinicians who participated in this study for allowing us to learn from their experiences, and to Tatianna Rivera for her assistance in data collection.

Declaration of interest

The authors report no financial relationships relevant to this article and no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

Funding

This study was funded by pilot grant funding from the Johns Hopkins School of Medicine's Division of General Pediatrics and Adolescent Medicine and by a medical student grant from the Johns Hopkins School of Medicine chapter of the American Medical Women's Association. Funds were used for day-to-day study expenses.

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Appendix A. Sample of interview questions used during qualitative data collection, as asked to children participants. Similar questions were asked of caregivers and clinicians

Barriers/facilitators

What things make it hard for you to take this asthma medication every day?

What things help you to take this asthma medication every day?

Asthma Medication Beliefs

What is your understanding of the purpose of this controller medication?

You mentioned children should/should not take asthma medications when they do not have symptoms? Why/why not?

You mentioned you worry about side effects from your daily asthma medication. What concerns do you have? Where or who did these concerns come from?
