# Towards Caregiver-Centric Health Technology in Intricate Care Situations

## A Case Study of Childhood Asthma Care in the Local Community

Jamie Flores
Perelman School of Medicine
University of Pennsylvania
Philadelphia, Pennsylvania, USA
jamie.flores@pennmedicine.upenn.edu

Anthonia Odarkor Odartei
School of Social Policy & Practice
University of Pennsylvania
Philadelphia, Pennsylvania, USA
odarteianthonia@gmail.com

Levia Airall Sutton
School of Nursing
University of Pennsylvania
Philadelphia, Pennsylvania, USA
levia@upenn.edu

Hita Kambhamettu
Department of Computer and Information Science
University of Pennsylvania
Philadelphia, Pennsylvania, USA
hitakam@seas.upenn.edu

Sonya Sanders
Philly Thrive
Philadelphia, Pennsylvania, USA
sonya@phillythrive.org

Kenrick Cato
School of Nursing
University of Pennsylvania
Philadelphia, Pennsylvania, USA
kcato@nursing.upenn.edu

Aviv Landau
School of Social Policy & Practice
University of Pennsylvania
Philadelphia, Pennsylvania, USA
landauay@upenn.edu

Andrew Head
Department of Computer and Information Science
University of Pennsylvania
Philadelphia, Pennsylvania, USA
head@seas.upenn.edu

## Abstract

This work serves to inform the design of better health information technology for intricate care scenarios. We focus on a situation involving a severe condition, child patients, rich know-how, and complex caregiver networks—childhood asthma in our local urban community. Conducting design investigations with 23 caregivers who are predominantly Black and single across 14 interviews and 2 workshop sessions, we offer the following observations. First, caregivers draw on rich knowledge about triggers, mitigations, and medication, which often reflect medical consensus, but occasionally conflict. Second, asthma care involves acute, highly stressful episodes, exemplified by caregivers' nighttime monitoring and management. Third, care systems are distributed among parent, child, broader family, and schools. This leads to decentralized information and responsibility, communication needs, and concerns around reliability of care. We conclude if health technology is to support this situation, it will mind community knowledge, intense acute episodes, and the decentralized and heterogeneous nature of care.

## CCS Concepts

• **Human-centered computing → Empirical studies in interaction design**.

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## Keywords

Pediatric chronic illness management, caregiver-centered digital health, distributed pediatric care networks

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## 1 Introduction & Related Work

Health technologies for chronic childhood conditions are only as good as our understanding of the situations they are meant to support. When the lived experiences of those caring for children with chronic conditions goes undocumented, the technologies we develop risk leaving unmet needs invisible and unaddressed.

Chronic childhood conditions involve care situations that are inherently complex, distributed across many people and institutions. For instance, Cha et al. have documented how successful management of pediatric type I diabetes requires shared responsibility among multiple actors [4–6]. However, prior research notes existing technologies can fail to acknowledge this collaborative structure, contributing to primary caregivers feeling solely responsible [12].

Childhood asthma, a condition impacting 4.5 million children in the United States alone [3], is a particularly salient instance of this challenge. Though technological innovations for asthma often target individual patients (e.g., [1, 13, 14]), care for pediatric conditions rarely rests with a single person. Parents must monitor closely and administer medications while navigating high levels of stress and fear [8, 16]. Beyond the responsibilities of parents, care is distributed amongst extended family, schools, and other institutional actors who share responsibility for a child's wellbeing, which requires complex collaboration and communication. Additionally, the child is themselves one of the parties involved in care, yet cannot bear the full responsibility, particularly at young ages.

Designing technology for pediatric asthma is further complicated by the substantial health disparities across communities. Asthma disproportionately affects low-income communities and racial and ethnic minorities [10]. Black children face significantly worse asthma outcomes than White children, with not only higher rates of the condition, but also more frequent emergency department visits and substantially higher mortality rates [3, 10]. The dynamics of care can differ as well, shaped by less flexible employment, financial strain, and the childcare options available to a primary caregiver [9]. As Prather et al. point out, research is needed into collaborative care dynamics and the kinds of challenges that caregivers experience within more marginalized groups [11].

The purpose of this work is to document the complexity of caring for children with chronic illness to inform the design of better health technology. We focus on childhood asthma as an exemplar case of high-stakes, community-based pediatric chronic illness management and center a community traditionally underrepresented in prior studies. Our goal is to make the strengths, challenges, and coordination efforts of caregivers more visible to those developing the health technologies with which they will interact.

Towards this goal, we conducted 14 interviews and 2 co-design workshops with 23 caregivers in a local community in Philadelphia. Members of our community were predominantly Black and single; many were managing severe asthma.

Our primary contribution is an empirical account of caregiver knowledge, nighttime difficulties, and coordination in pediatric asthma management as it arose in this community (Section 3). These findings advance understanding of the complex realities of community-based chronic illness care that health technology must interface with to meaningfully support caregivers like those in our study. A supplemental contribution is a set of directions for exploration in the development of caregiver-centric health information technology to better fit these caregivers' experience (Section 4).

## 2 Methods

We conducted qualitative interviews and co-design workshops focused on the following question:[1]

> *What does the caregiver experience look like in our local community, and where are opportunities for health technology to mind the complexity of this care experience?*

***Participants.*** We recruited 23 female caregivers living in Philadelphia (Table 1). Outreach was done in partnership with Philly Thrive, a community environmental justice organization dedicated to advocacy and support for communities impacted by a recently shutdown South Philadelphia oil refinery. 14 of these caregivers participated in qualitative interviews (compensated $120 USD), and 9 in one of two design workshop sessions (compensated $200 USD).

Participants were predominantly Black, single mothers with high school-level education, caring for multiple children, including some who had severe asthma. More specifically: participants were between 23 and 68 years old, with a median age of 43.5. 91.3% reported their race as Black and 8.7% as White. Participants reported their highest level of education as follows: 8.7% less than high school education, 56.5% high school diploma or GED, 21.7% some college or associate degree, 4.3% Bachelor's degree, and 8.7% preferred not to say. The majority of participants reported marital status as single (78.3%), and the remaining as either divorced (8.7%) or married (13.0%). Participants had anywhere from 1 to 8 children with the median and mode being 3 (Table 1).

***Interviews.*** Interviews were approximately one-hour long and held over video. One of the authors conducted the interviews, following a semi-structured interview guide covering their experience with asthma, the medical system, and electronic health records and thoughts about raising awareness of asthma in the local community.

***Co-Design Workshop.*** Where our interviews provided a deep perspective into individuals' experiences, our design workshops allowed us to develop ideas for better technological support with members of the community. We held 2-hour-long workshops, hosted at the headquarters of our community partner, Philly Thrive. The workshop followed a 3-part Note & Vote process. Using sticky notes and a central white board, participants individually brain-stormed challenges and strengths related to asthma care; then possible solutions; and then used dot voting to work towards convergence on higher-priority problems and solutions. At each stage of ideation, participants were asked to explain their ideas with the group and build off each other's ideas.

***Analysis.*** These sessions yielded audio recordings, screen recordings, photographs of participant-written ideas, and responses to background questionnaires. Audio recordings were transcribed using Scribie, an automated transcription service. We conducted a thematic analysis of all transcripts, referring to screen and audio recordings as needed, following established inductive thematic analysis methods [2]. Analysis took place in multiple passes: first, the lead author created a set of codes through an open coding pass, all relating to answering questions about asthma severity, knowledge, frictions, coordination in asthma care, and child self-management. To validate the coding and establish reliability, the last author independently reviewed the codes following the open coding pass on approximately 10% of the data, examining whether code definitions and their application were consistent and well-grounded in the transcripts. Discrepancies were discussed between the two authors until consensus was reached, leading to refinements of the codes and criteria for applying them. The first author then coded the entirety of the data.

## 3 Findings

Our analysis resulted in three themes, all reflecting complexities of the care situation that we believe should be minded in health technologies servicing this group. This includes strengths (Section 3.1) and challenges (Sections 3.2 and 3.3). We support our review

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[1] All research activities received review from our institutional ethics review board.

**Table 1: Participant Backgrounds and Demographics**

| Pseudonym | Gender | Age | Race | Education | No. of Children | Marital Status | Study Format |
|---|---|---|---|---|---|---|---|
| Katherine | Female | 31 | Black | High school diploma or GED | 3 | Single | Interview |
| Alicia | Female | 27 | Black | Some college or associate degree | 1 | Single | Interview |
| Christina | Female | 48 | Black | High school diploma or GED | 4 | Single | Interview |
| Denise | Female | 44 | Black | High school diploma or GED | 4 | Single | Interview |
| Gabby | Female | — | Black | Prefer not to say | 2 | Married | Interview |
| Janet | Female | 45 | Black | High school diploma or GED | 4 | Single | Interview |
| Jenifer | Female | 55 | Black | Bachelor’s degree | 2 | Married | Interview |
| Jill | Female | 36 | Black | High school diploma or GED | 3 | Single | Interview |
| Keesha | Female | 48 | Black | Less than high school | 5 | Single | Interview |
| Kimberly | Female | 43 | Black | High school diploma or GED | 2 | Divorced | Interview |
| Lisa | Female | 41 | Black | High school diploma or GED | 8 | Single | Interview |
| Nia | Female | 46 | Black | Some college or associate degree | 4 | Single | Interview |
| Olivia | Female | 36 | Black | Prefer not to say | 3 | Single | Interview |
| Rochelle | Female | 42 | Black | Less than high school | 8 | Single | Interview |
| Natasha | Female | 55 | White | High school diploma or GED | 7 | Divorced | Focus Group |
| Laura | Female | 23 | Black | High school diploma or GED | 2 | Single | Focus Group |
| Simone | Female | 62 | Black | High school diploma or GED | 1 | Single | Focus Group |
| Shonte | Female | 49 | Black | Some college or associate degree | 3 | Single | Focus Group |
| Nicole | Female | 32 | Black | High school diploma or GED | 4 | Single | Focus Group |
| Maya | Female | 40 | Black | High school diploma or GED | 2 | Married | Focus Group |
| Angela | Female | 53 | Black | Some college or associate degree | 3 | Single | Focus Group |
| Michelle | Female | 39 | White | High school diploma or GED | 3 | Single | Focus Group |
| Toni | Female | 68 | Black | Some college or associate degree | 4 | Single | Focus Group |

of findings with counts of how often observations arose in our analysis (e.g., “(12)” refers to “12 participants”), de-identified quotes, and references to participants via pseudonyms.

## 3.1 Theme 1: Rich, Deep Knowledge, at Times Apart from Medical Consensus

Our participants were not those for whom basic educational interventions were needed. Given their central role in managing a severe condition, they demonstrated comprehensive knowledge of asthma care as it pertained to their child. Participants regularly spoke with us about topics spanning the gamut of comprehensive asthma care, including medications (12), appropriate escalation of care, (8), asthma triggers (14), and allergen avoidance strategies (7). They regularly shared with us advanced knowledge, such as about symptom monitoring (13), participants spoke to us about how they identify wheezing through auditory assessment (7) and recognize abnormal work of breathing through visual observation (7). For instance, Katherine recalled subcostal, supraclavicular, and suprasternal retractions used by medical professionals to identify abnormal pressure in the lungs: “*have your child sit up, pay attention to their neck in the area right below their ribs, see if it’s caving in.*” We note this not so much to indicate that caregivers should not have had this knowledge—they had years of experience managing an intense condition for their child—but rather to indicate the wealth of knowledge with which caregivers navigate daily care.

Participants often showed knowledge of and described use of various home remedies (12): these included steam treatments, air purifiers, honey, garlic, herbs, fruits, and vegetables. Participants had developed calming techniques (7) to manage the bidirectional relationship between emotional state and asthma symptoms.

For some caregivers, home remedies were preferred over conventional medical recommendations (3). For example, Laura said, “*doctors are not right all the time, so I like to do everything natural for my two-year-old.*” Shonte described home remedies as helping to avoid the friction of seeking medical attention: *“I don’t have to deal with the bureaucracy and all the other stuff that goes along with this. If that tea is going to make sure that she gets enough sleep or being in the bathtub is going to help her breathe.”* Another situation where we saw some divergence from medical consensus was in approaches to activity restriction. Clinically, activity restriction is not typically recommended as inability to participate indicates poorly controlled asthma needing stronger controller medication [7]. However, eight participants imposed activity restrictions as asthma control.

## 3.2 Theme 2: Acute and Stressful Care Episodes at Nighttime

One of the most stressful situations caregivers described was at night. With asthma, lung function can worsen overnight [15]; caregivers were responsible for monitoring their children’s breathing and supporting them through the night when asthma flared. 11 caregivers mentioned difficulties with managing nighttime symptoms, including situations where the child would be “*up all night coughing and crying*” [Nicole] or “*would cough out of his sleep real bad*” [Janet]. This could lead to “*so many sleepless nights*” [Katherine].

This time of night could cause caregivers considerable anxiety and fear (3). Christina worried that asthma symptoms would progress while she was asleep, and expressed, “*What if I’m sleeping too hard and this child is not able to cry loud enough or get my attention?*” Kimberly described concerns around being able to adequately administer care, telling us, “*I’m like, praying like, Lord, please don’t* *let me mess up 'cause I'm taking medicine in my own hands, like, I'm a nurse.*" Nighttime asthma episodes could add additional stress when it became apparent that caring for a child might come into conflict with one's work schedule: as Katherine told us,

> "*... I have to be up all night and still get up for work at 6:00 o'clock. And my baby screamed and hollered and cried and looked me in my eyes and said, 'you need to tell them your child is sick' ... And I broke down... while your child feels like they're losing their life, you feel like you're losing your mind.... you're in a battle between, I have to provide for you, but I have to be here for you.*"

Participants described extensive efforts towards managing nighttime symptoms (6). Katherine would stay awake holding the child in an upright sleeping position, which seemed to better support the child's breathing. She said, "*I had to sit up so that she could sit up on me as she tries to sleep so that her airways could open up just a little bit, 'cause laying down doesn't help.*" Kimberly described the need for frequent medication administrations throughout the night in an attempt to stay ahead of severe symptoms: "*My only fear was oversleeping. You're on a schedule now with this child. You [gotta] keep waking up every four hours.*" Caregivers monitored their children's asthma symptoms throughout the night even while the child was asleep. Rochelle described of her child, "*sometimes I [gotta] wake [her] up out of her sleep because she not breathing right.*" Another used a baby monitor to monitor the breathing of her 11-year-old.

## 3.3 Theme 3: Distributed Care Coordination across Multiple Actors and Settings

Rather than involving primarily one main caregiver, asthma care involved coordination across many people and contexts, with multiple opportunities for breakdowns. Caregivers had to coordinate with their child (18), schools (10), partners (4), daycares (1), extended family (3) and other members of the community (8). Each of these stakeholders had different responsibilities, and there could be incongruency between the expectations of the role that they are intended play and their ability to do so. Effort in coordinating care arose in several notable situations.

*3.3.1 Teaching children asthma self-management.* Over time, a child has to learn how to care for themselves; caregivers assume much of the role of teaching that child self-care. With particularly young children, teaching focuses on helping the child alert the caregiver or others if they are having trouble breathing (7). Caregivers taught their children "*the importance of speaking up*" [Alicia], including at night: '*So if you are up and you're struggling and I'm asleep, don't struggle, wake me up*" [Kimberly]. As children gained independence, caregivers taught them to manage their medications (8). One of the first steps of this process was teaching the child to carry their rescue inhaler with them at all times, and how to use it in case of emergency (6). For Olivia, for instance, this involved teaching the child to carry an inhaler with her in a special purse and stressing the importance of using it:

> "*... if I'm not with you and you don't have your purse, you're not gonna be able to get, you don't have your safety net. The safety net is there to keep you alive. Everybody don't know what to do in a case of an asthma attack... if you feel as though you can't breathe, you have your inhaler. And you can use it.*"

Furthermore, caregivers taught their children the importance of taking controller medication (3), a daily medication meant to reduce symptoms and prevent acute attacks. Eventually, caregivers would leave full responsibility to the child (2); prior to this point, caregivers would continue to support them by picking up prescriptions or occasionally reminding the child to take medication. Caregivers also taught their children about asthma triggers: what they are; how to avoid them; and if unable to avoid them, to have the inhaler available. They taught their children about how various factors—physical activity (5), environmental allergens (2), secondhand smoke (1), and weather changes (1)—could trigger their asthma.

*3.3.2 Reliability of care partners.* For the caregivers in our study, the broader community administering care included myriad actors in asymmetric roles. Those in more peripheral roles could cause considerable stress to those playing more central roles. One of these more peripheral actors was schools, which 10 caregivers described coordinating with. Schools needed to be prepared with knowledge and medication to help children manage their asthma. This could involve some effort—parents had to get the right information to the schools (5), sometimes by handing over paper records (4) with medication instructions and physician approval (1), or by having the doctor call the school nurse (1). One participant described this as going "*through all these loops and [back] holes just to, for you to be able to allow a kid to bring medication*" [Olivia].

Sometimes, schools provided the reliable support their kids needed; in other situations, caregivers were concerned around the reliability of the care provided. Toni described a situation where the necessary staff was not consistently on duty: *"... nurse, you wasn't in for a whole week, so you couldn't help her with the pump? I had to run to the school and take a pump. So what good is it for me to give you the pump if you ain't there this week?"* Even when the school was prepared to give medication, caregivers needed to use common sense about who was responsible for administering it. For instance, Nia described that their child needed to know how to take their medication because by the time an asthma attack hit, the child may need to be already taking their medication rather than taking the time to go to the nurse.

*3.3.3 Family Coordination.* Providing care could sometimes involve coordination among multiple adult caregivers, including among partners (4) and with extended family (3). Some described the extended family as crucial pillars of support. In some cases, the caregivers' knowledge of asthma came from their family, as for Alicia who said her "*sister's daughter also suffers from asthma... so everyone in [my] support system, they know what to do, what to look for.*" Kimberley described the role her mother played in her children's asthma care: "*Both of my kids they was blessed to be with my mom up until they went to kindergarten... When he had his asthma flares, she knew what to do 'cause my sister and my dad had it. So it definitely killed my nervousness or anxiety.*"

Others experienced issues or costs coordinating with extended family, such as Toni, who said, "*not one family member will watch my grandson. Not one. No, no. They don't want that in their house...*

*because if something goes wrong with something.*" Many of the caregivers were single (78.3%) or divorced (8.7%); in some of these cases, caregivers needed to coordinate with the child's father, like Katherine did when she handed off medications to the child's dad (1). Kimberly described reading her child's EHR after the child's medical visit to "*make sure it's nothing [I] didn't miss since I don't take him to the doctors. His dad is not… He is okay, but he is not really good with explaining what the doctors say.*"

## 4 Discussion & Future Work

Our findings are shaped by the community we worked with—they represent primarily the experiences of single Black mothers in Philadelphia, managing their children's severe asthma. We do not conjecture that they represent the most important issues for all caregivers of asthma, but rather we offer them to enrich the view of caregivers as technology is developed for them. An additional limitation of our study is its reflective methodology; Participants were sometimes discussing events years in the past, and we may have missed aspects of care that could only be observed through observation or more contemporary reflection. Future work should continue to enrich accounts of childhood asthma care with additional communities and forms of engagement with participants. Amidst this context, and grounded a combination of themes in observations from both interviews and workshops, we offer the following provocations to motivate future work:

***Approach design acknowledging dual knowledge and burden.*** In our design workshops, issues around asthma were sometimes described by caregivers as both strengths and challenges—for instance, administering medication, staying up all night, and keeping children calm. Section 3.1 describes the deep knowledge caregivers develop, and Section 3.2 the difficulty of care despite it. An advantageous stance for designing technology, whether decision support, tracking tools, educational materials, should be to mind this caregiver knowledge while still assisting them with significant burdens. For instance, could caregivers be facilitated in sharing their knowledge with those in their families and broader communities? Are there ways to support productive exchange around home-grown remedies, while also breaking down barriers to understanding useful clinical recommendations?

***Defuse stressful, acute nighttime events.*** Nighttime symptom management represents an important class of asthma care episodes: it involves high stress, takes place at a time of day where one's personal resources are depleted, and requires sensitivity to the child's physical symptoms and intervention. One preliminary idea of an assistive technology was discussed by three participants in the design workshops: wearables to help with symptom detection. For instance, in Natasha's words, "*maybe they can find out what the child's body does before the asthma actually takes effect… like a device that'd be a watch or something that you have on your body.*"

***Facilitate coordination and instruction across child, caregiver, and network.*** In the best case, health records and instruction would be easily accessible to the broader community caring for a child, and packaged in a way befitting the person in each role. They would support children on their journey to gradually understand their condition in greater sophistication, perhaps helping them keep track of their growing responsibilities to self-monitor and self-administer (Section 3.3.1). And they would impose less burden on a caregiver to share information with other responsible parties like schools (Section 3.3.2), while facilitating the kinds of knowledge exchange that greatly helped some caregivers we spoke with (Section 3.3.3) to occur in places where one has less personal familial connections to asthma.

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