At the Interface of the Healthcare System and the Community: Insights from an Academic-Community Partnership in Camden, New Jersey

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"D" oc, we have it really bad here," said a teenager from Camden, New Jersey. The statement was offered during a focus group about improving care for asthmatic children in Camden. Although the questions focused on issues within the healthcare system, the children spontaneously opened the door to their world and what they perceived as critical barriers to asthma control in their community: poverty, unemployment, incarcerated parents, drug overdoses, gun violence and related deaths. "Everyone is dying around us," one child said. The children were pointing researchers to the elephant in the room: that the tumultuous realities of day-to-day life in Camden are also a root cause of poor asthma control.

Asthma is a common and expensive childhood condition eroding the quality of life of children and families across the country. The disease affects 8.6 percent of American children (PDF) and generates approximately $8.3 billion in annual healthcare costs, 28 percent of which is attributed to acute care use. In Camden, New Jersey, one of the poorest cities in America, 32 percent of school-aged children have asthma. From 2002 to 2012, Camden experienced a 95 percent increase in pediatric asthma-related hospitalizations despite a 13 percent decrease in total pediatric hospitalizations.

Funded by the Emergency Medicine Foundation, and through an academic-community partnership between the University of Michigan, RAND Corporation, and Camden Coalition of Healthcare Providers (Camden Coalition), we sought to identify patient-centered interventions to reduce avoidable asthma-related acute care use (i.e., emergency department visits and hospitalizations) and improve childhood asthma outcomes. We incorporated the views of our community partners including asthmatic children and
Community partnerships helped illuminate how healthcare interventions must be adapted to local needs.

Forming an Academic-Community Partnership in Camden, New Jersey

The partnership between the University of Michigan, RAND, and Camden Coalition brought together clinical expertise, research rigor, and community networks. In 2012, leadership from the Camden Coalition and researchers from the RAND Corporation co-identified a need for pediatric interventions to reduce acute care use among children in Camden. Through evaluation of all-payer hospital claims data obtained from the Camden Coalition and conversations with community partners, we identified asthma as a key population health challenge in Camden with high and increasing rates of asthma-related acute care use. After goals and objectives for the partnership were defined, the Camden Coalition, RAND, and the University of Michigan partnered on a proposal to identify patient-centered interventions to reduce avoidable acute care use among asthmatic children in Camden.

Keeping Our Finger on the Pulse of the Community

To keep our finger on the pulse of the community, we held quarterly meetings with a community advisory board (CAB), which included healthcare providers, community members, a representative of the faith-based community, health services researchers, a school nurse, and representatives from the Camden Coalition. These partners provided critical insights into the community’s needs: they shared the expertise they have gained by seeing patients in their offices; they explained the environmental barriers related to low-income housing in Camden; and offered lessons learned from wrestling with the poverty facing many Camden families. The CAB also helped design the focus groups, vetted potential interventions, and guided the interpretation of findings.

The study involved three phases. In Phase 1, we used a cluster analysis of claims data from Camden hospitals to identify five groups of children with distinct patterns of asthma-related acute care use. Patients in the groups had increasing levels of acute care use, ranging from few hospitalizations or emergency visits to “super-utilization” of acute care services. In Phase 2, we convened four focus groups of asthmatic children or their caregivers from the low- and high-utilizer groups. Participants ranked potential asthma interventions and suggested interventions that would help them manage their asthma. In Phase 3, the results of Phases 1 and 2 were shared with a panel of local stakeholders, which rated the interventions and recommended which should be implemented.

A Crash Course in Healthcare Systems from Asthmatic Children and Caregivers

Ambulatory Care

Patients and caregivers expressed a desire for changes to how asthma is treated in ambulatory care settings and identified numerous barriers affecting their access to care. They expressed a need for evening hours, weekend appointments, and walk-in availability. There was also interest in a 24/7 nurse hotline that could help make decisions about where to seek care.

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The difficulties that participants experienced accessing primary care resulted in higher rates of acute care use. For example, patients and families described seeking care in the ED after a failed attempt to be seen in the primary care setting. One caregiver explained, “I would call [the] doctor; they’d be like, ‘You’ve got to leave the nurse a message and she’ll call back.’ I’ve called like eight o’clock in the morning, she didn’t call back until like five; I’m already at the emergency room.” Long wait-times, scheduling difficulties, and pharmacy delays were also cited as reasons to go to the ED instead of the primary care clinic. In contrast, parents liked the immediacy of the ED: “I guess you get the relief factor. You know you ain’t got to wait and you know they got everything they need right there on site.”
Several parents described having their child seen in primary care, only to have the severity of the asthma exacerbation increase later: “The kid can be real sick, they give them steroids at the doctor, then they send them home...They wait 'til too late to send you to the hospital. And then when we got to the hospital, she needed steroids, oxygen, and all these things.” Negative experiences like these led patients and caregivers to forego the primary care office and to seek care in the ED first.

**Hospital-Based Care**

Focus group participants identified hospital-based interventions that would help them manage their asthma more effectively. The children participants were interested in having easier access to their medications and supported having the hospital provide prescriptions for asthma medication refills. Meanwhile, parents showed an interest in having asthma action plans be administered in the ED and expressed that the ED should communicate with the child's primary care doctor after each emergency visit. Patients and parents expressed that distinguishing between low- and high-severity asthma attacks is difficult. As one adolescent participant said,“I can't schedule appointments because one minute I could just have a sharp pain and the next it stops...so I just go to the ER instead of trying to schedule an appointment.”

Both parents and children in the focus groups wanted their inpatient clinicians to provide more feedback for how to avoid future hospitalizations. One participant suggested “Giving you a list of things you can do to control your asthma.” Another proposed, “They can ask you questions on why, or how you got so sick...and then most likely you won't do it again.”

**School-Based Care**

Patients and their caregivers agreed that school-based interventions could improve asthma-control and identified three ways in which schools impact asthma: 1) the prevalence of asthma triggers, 2) poor asthma-control practices, and 3) being unprepared to address asthma exacerbations.

Regarding asthma triggers, participants identified the need to address environmental asthma triggers in schools, including dust, mold and bugs. Patients also recommended that schools do a better job of prohibiting tobacco smoking by students at school.

On the school's role in controlling asthma, children and their family members described rules restricting students' use of inhalers and other asthma medications during school hours. One parent described a common frustration: “The school that my son go [sic] to, his nurse, I'll tell her when he has to take his asthma [medication] but she said that their rule is if it's not real bad they...won't give it to them.”

The families described room for improvement in how schools respond to asthma exacerbations, emphasizing the need for response plans and training for staff on recognizing and addressing these flare-ups. As one parent said, “They didn't know what to do. They called me, they did one treatment, one puffer, but they still had him sitting there, like belly breathing, when I got there...we had to call the ambulance.”

**Don't Forget About Social Determinants of Health**

During the focus group with teenagers with high rates of acute care use, the participants initiated a conversation about the role that poverty, stress, trauma and violence play in their lives. Participants shared stories of working multiple jobs, caring for sick family members, surviving domestic abuse, missing incarcerated parents, losing friends, witnessing violence, and avoiding gangs. When asked how these social factors affected their asthma, one participant explained, “The stress and the worry, that's the main thing. Stress, because you're stressed about getting your parents and your family in a better situation, and a better place, and worried about trying to sit there and provide for yourself and your family...[T]hat builds up a lot of stress...it gets to a point where it's too overwhelming.” To help asthmatic youth manage asthma symptoms arising from this stress, the children and parents suggested creating a school-based clinic, equipped with inhalers and nebulizers, where children could go to calm down and have their asthma monitored. When participants with lower levels of acute care use were queried about stress and asthma, their answers were remarkably different. Some cited typical teenage stresses: homework, sporting events, tension with parents; others asked how stress could possibly affect asthma. These disparate findings underscore the importance of including patient voices in conversations about how to address barriers to care.

**Seeking Care Delivery Solutions at the Intersection of the Healthcare System and Communities**

This academic–community partnership revealed insights from the Camden community regarding how to redesign the health system to better respond to its needs. Our experience illustrates the importance of prioritizing community voices. Without these
Our experience illustrates the importance of prioritizing community voices. Without these voices, we would have been blind to the needs and nuances of the Camden community, and would likely have arrived at very different conclusions about how best to address Camden’s asthma burden.

The next steps of this project entail implementing the interventions the community identified in Camden’s schools and healthcare facilities and evaluating their comparative effectiveness at reducing avoidable asthma-related acute care use and improving outcomes. The Camden City school district and all three major pediatric practices have agreed to participate. Based on our findings, clinical interventions will include asthma trigger screenings, care coordination, and asthma education. School-based interventions will include streamlining the process for administering asthma medications in schools; establishing a school-based asthma clinic; training for school staff; and inspecting buildings for asthma triggers.

Over the last decade, the scientific community has spent billions seeking to improve asthma care. Despite these efforts, the United States has seen no significant reduction in overall asthma mortality, even as asthma mortality has decreased in other high-income countries. This failure may, in part, be a result of the one-size-fits-all approach taken by researchers and healthcare providers. Many interventions fail to incorporate the perspectives of community members and overlook the social needs of pediatric asthma patients. Academic-community partnerships like the one described above can be a critical step in developing health interventions that are adapted to the realities of a community’s situation. Until the healthcare community learns to give patients a stronger voice in their own care, we risk devoting more time and money to interventions that fail to reach patients or meet the true needs of our communities.

Endnotes


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