Center for Health Care Strategies

Johns Hopkins HealthCare and Johns Hopkins Children's Center: Expanding Interdisciplinary Teams to Care for Patients with Complex Needs

t first glance, care approaches for children with sickle cell disease, children with asthma, or mothers with postpartum depression appear to have little in common. Yet despite the differences in diagnoses, these patients and their families often have similar needs that affect their health, created by social risk factors such as poverty, unstable housing, joblessness, lack of transportation, racism, and trauma. Regardless of diagnoses, enabling patients to better navigate the health care system and address their health-related social and behavioral needs in tandem with their medical needs can support improvements in health and well-being.

With patient and family needs front and center, Johns Hopkins HealthCare teamed up with faculty in the Johns Hopkins Children's Center to lead three pilot programs to improve care for children with sickle cell disease, children with asthma, and

AT-A-GLANCE

Organization: Johns Hopkins HealthCare and Johns Hopkins Children's Center

Goal: Make the health system easier for families to navigate, build trusting relationships with children and families, and provide support to address patients' social risk factors and behavioral health needs

Population: Children and adolescents with sickle cell disease or asthma, mothers with postpartum depression

Featured Services: Support from community health workers and case managers, teambased care model, intensive case management, integrated behavioral health support, and care delivered at home, in school and, in the case of mothers, at wellbaby visits

mothers with postpartum depression. Under the Center for Health Care Strategies' <u>Advancing Integrated Models</u> (AIM) initiative, the three projects used similar strategies to provide integrated and trauma-informed complex care to these patient populations.

COMPLEX CARE INNOVATION IN ACTION

This profile is part of an ongoing series from the Center for Health Care Strategies (CHCS) exploring strategies for enhancing care for individuals with complex health and social needs within a diverse range of delivery system, payment, and geographic environments. **LEARN MORE** »

Strategies used in the pilots include: (1) care teams that share knowledge and provide for medical, behavioral, and social needs; (2) community health workers (CHWs) and case managers incorporated as care team members; and (3) care delivery in nontraditional settings, such as homes and schools. The result is care that more comprehensively helps children and families with complex needs while also reducing costs.

"If you have a child with a chronic illness, there's often more needs from financial strains and psychosocial stressors in those families," says Megan Tschudy, MD, MPH, who leads the asthma program at Johns Hopkins' Harriet Lane Clinic, a pediatric primary care center. The clinic has 8,000 patients, with 90 percent of patients covered by Medicaid or the Children's Health Insurance Program. More than 30 percent of clinic patients have chronic conditions that contribute to health disparities compared to populations not covered by Medicaid. Chronic conditions also can lead to high rates of children missing school due to illness, which can contribute to broader educational inequities.

Role of Community Health Workers

CHWs are key members of the clinical care teams and vital to all three pilot programs. They build trusting relationships with families by spending time with patients and caregivers, listening to their concerns, and giving supportive help. CHWs maintain regular contact through phone calls, text messages, and in-person visits when possible. They guide families to resources and give hands-on help in making connections, instead of just handing over a flyer with a list of organizations to call.

When Leverisa Smith became a CHW with the pediatric sickle cell disease program, she learned that parents of children with the inherited blood disorder might also have the disease and that it can affect cognition. Because patients may need follow-up visits, imaging, or transfusions, Smith sends frequent reminders to families, especially if a parent also has sickle cell disease. "They have intentions to keep up with care, but they forget, or they misplace phone

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> Leverisa Smith, Community Health Worker, Johns Hopkins Children's Center

numbers and paperwork," she says. She calls to see what the problem is if a patient misses a clinic session, hasn't gone for needed lab work, or didn't pick up a prescription.

Smith also calls or texts families that have lost touch with the program. By reaching out personally, she has been able to help families with any barriers, restoring consistent care for children. That makes families "more satisfied," she says. "They're willing to come to appointments more because they feel like they're being heard and listened to."

CHWs share what they hear and see in their work with the rest of the care team, providing insight into what might be causing patients' difficulties in following treatment plans, keeping appointments, or communicating with providers.

Patient Story: Close Navigation Produces Significant Health Benefits

Shantia Alderman, a CHW with the asthma program, recalls twin boys who had severe asthma attacks and frequent hospitalizations. She visited the family's apartment and found mold — an asthma trigger — growing so extensively it was attaching to furniture.

The local housing authority had promised to move the family, but there had been no action. Alderman went to court with the boys' mother over several days, resulting in the agency finding a house for the family. "It took for us to get involved for them [housing officials] to move their feet," Alderman says. Having help from a CHW means "you've got somebody behind you, another voice other than your own." The family moved and the children are now doing well.

"Community health workers, some of whom have lived experience (i.e., they come from and/or live in the same communities as they families they are serving), are able to connect and bond with caregivers and families in a way that our clinic staff is not able to do," says Barry Solomon, MD, MPH, who is division chief of general pediatrics and leads the maternal depression program. Mothers for the program are identified during wellbaby visits through routine depression screening, but some mothers who need care may still not be identified during these visits. Clinic staff sometimes miss the signs and some mothers may feel hesitant to disclose their depression and/or be unable to engage in care.

Shannon Adams, a CHW at the clinic, helps the mothers feel comfortable talking to her about things they may be hesitant to discuss with their primary care providers. To encourage that trust, she often walks or rides the Metro with them, going to appointments or to apply for services. She sends reminders and often coordinates transportation for their children's medical visits as well. "It's less like you're a social worker or provider and more like a friend," she says.

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> Barry Solomon, MD, MPH, Division Chief, General Pediatrics, Johns Hopkins Children's Center

CHWs in the pilot programs previously worked as certified nursing assistants and patient care technicians. All were trained for their CHW roles by a Baltimore jobs

program and certified by the state of Maryland. They also took part in trainings in trauma-informed care to learn how traumatic experiences, such as childhood neglect, violence, and racism affect a person's health and well-being.

Two of the pilot programs have case managers on their clinical teams that enroll patients and families into programs, conduct screenings, and monitor treatment plans, goals, and progress. Case managers refer the family to CHWs for specific help, such as applying for housing or receiving reminders about medication. The case manager has a larger cohort and "oversees the big picture, and I work more closely with the patient," says CHW Adams.

Patient Story: Personalized Support for a Mother with Complex Needs

One young mother came into the maternal depression program with a lot of anxiety, an infant, and an unsupportive husband. She had trouble managing appointments and understanding what her providers were telling her. The patient's CHW, Shannon Adams, helped her get medical insurance, find a primary care doctor and specialists, receive psychological testing, and apply for disability income. After working with the CHW for two years, the patient now has her own apartment, drives a vehicle, and is entering a workforce program for people with disabilities.

Integrated Care Team Approach

Interdisciplinary Team

Patients and families enrolled in one of these three programs at Johns Hopkins benefit from a interdisciplinary team focused on their care. In addition to CHWs, team members include doctors, nurses, social workers, behavioral health providers, and others, drawn from the specialty areas most needed by patients in each program. Weekly remote meetings keep team members updated on current and new patients. "We work synergistically to provide services," says Tschudy of the asthma program.

As part of the interdisciplinary team, CHWs provide greater understanding about the children and families they work with — awareness that clinicians might not normally get in medical visits. For example, the team might learn from the CHW that a family member has become ill or lost their job, affecting the mother's ability to bring the child in for a visit. As team members, CHWs also enter information into the electronic medical record system to keep others on the team informed.

Having integrated teams helps reduce delays and decreases the time that health care providers spend requesting advice or care from other departments and centers.

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According to Emily S. Rao, MD, MA, MS, who is associate program director of the Pediatric Hematology-Oncology Fellowship and co-leads the pediatric sickle cell program, having connections that were formed in integrated care team meetings with specialists in chronic pain, neurocognitive testing, and more helps her patients receive services faster and more easily.

Behavioral Health Providers

Behavioral health providers help care teams support patients' mental health needs. Integrated care in the sickle cell disease program includes having a psychologist see patients after they turn 12 years old to support their growing ability to manage their own care as they prepare for adulthood. That transition period readies patients to independently manage their disease by talking with them about what sickle cell is, its treatments, complications, and when to call their team for help. Depending on individual needs, some patients may meet with the psychologist more often.

Mental health care, says Rao, carries a stigma that makes accepting behavioral health care "an uphill battle" with some families. By building relationships and making an annual meeting with the psychologist a routine part of the transition process for all patients, it "removes some of that stigma and barrier," she says. It also helps normalize having a behavioral health provider on the clinical care team. Having insights about behavioral health at team meetings has improved team awareness of what children and families experience regarding pain,

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James F. Casella, MD, Director, Pediatric Hematology, Johns Hopkins Children's Center

depression, and other disease effects. James F. Casella, MD, director of Pediatric Hematology and the Basic and Translational Research Program for Sickle Cell Disease and co-lead of the program, points out: "One of the major reasons our program was instituted was to address mental health needs that might otherwise go unrecognized and complicate the care of sickle cell disease. Having psychologists and an embedded psychiatrist with experience in pain management has provided an opportunity for the staff to enhance their skills in this area and dramatically improved the care of our patients."

Many mothers at Johns Hopkins Children's Center have had traumatic experiences in their lives, so screening for and addressing underlying or chronic mental health conditions is an important aspect of care. The maternal depression program's CHW and case manager can connect patients with behavioral health services in the clinic or near where they live, if they prefer. The pilot programs' integrated teams may have long-term effects on health care that go beyond the individual patients served. At the Harriet Lane Clinic, 55 pediatric residents train each year in providing primary care, with medical and nursing students rotating through as well. These experiences help them see the value of integrated care teams and the benefits of having CHWs as team members, Tschudy says. That may encourage residents and students to advocate for such innovations in their future practices. "For me, that's really exciting," she says.

Delivering Care in Non-Traditional Settings

One tenet of the three pilot programs is to "meet families where they are." That means understanding their needs and challenges as well as, quite literally, meeting them in the community, outside of clinic appointments.

Home visits can screen a child with sickle cell disease for unmet needs or check for environmental asthma triggers, such as pest infestations or mold. CHWs may accompany a parent to an office or agency to get needed services or meet up to talk in a park or library.

Prior to the COVID-19 pandemic and related restrictions, an asthma program CHW would visit children's homes and schools. The CHW would bring a prescribed asthma controller to each location and provide education about the condition and its treatment. At schools, the CHW delivered the controller inhaler to the nurse or authorized staff member so the child could have it for daily in-school use.

Outcomes

Initial results from using integrated complex care strategies in the pilot programs are promising. A few highlights include:

- Pediatric asthma: From January 2018 to January 2021, asthma controller use increased while symptoms and the need for steroid treatments decreased.
 Emergency department (ED) visits declined more than 50 percent and inpatient admissions were down more than 60 percent. Length of inpatient stays dropped by one day, indicating that children's asthma conditions were less severe. There was a cost savings of about \$5,000 per patient.
- **Pediatric sickle cell disease:** ED visits, inpatient admissions, and opioid prescriptions all decreased at six months, one year, and two years post-enrollment. Outpatient clinic visits increased, showing a shift in where care is delivered and possibly a growing emphasis on preventive care.

• **Maternal depression:** Costs decreased for ED visits and inpatient admissions for women and their children. From one year before program enrollment to one year after, the program achieved a savings of about \$860 per patient. With help from the program's CHW and case manager, about half of patients connected with a mental health provider. "That's a much higher rate than we saw when mothers did not have this level of support," Solomon says.

Challenges and Lessons

COVID-19

The COVID pandemic stopped most home visits and in-person activities for the pilot programs. While CHWs used to see patients and families during clinic appointments as well as during home and community visits, the pandemic prevented them from connecting in person for more than 18 months. Even when some patients returned to clinics, CHWs were not able to join because only a limited number of providers could be in the clinical space.

Instead, CHWs worked remotely from their homes. They used text messages and phone calls to check on families, respond to needs, and connect with providers about concerns. In late 2021, some CHWs returned to their work sites two days a week. They plan to return to having some in-person time with patients and caregivers during clinic visits.

Trauma-Informed Care Training

Before COVID, the plan for trauma-informed care training in the pilot programs centered on training CHWs and having them become trauma-informed care trainers for their integrated care teams. Those plans were undone by the overwhelming demands of the pandemic on clinical staff and restrictions on in-person trainings, but they hope to resume trainings for other staff once conditions improve.

While remote communications were helpful during the pandemic and, in some cases, gave CHWs more flexibility, having care services embedded in the clinic is important. Face-to-face interactions between patients and families with CHWs and providers were disrupted, making it harder to maintain continuity of care.

Program Funding and Sustainability

Funding and sustainability remain ongoing considerations for the programs. "The AIM initiative helped us demonstrate the worth of the integrated teams to our primary insurer, Priority Partners, to get their buy-in," says Tschudy. That helped the program think about how they can spread their approach to other sites and populations.

The asthma and maternal depression programs, both housed within the pediatric primary care clinic, have been approved for an additional year of funding from Priority Partners. They are working closely with leadership to ensure more sustainable funding.

Next Steps

The maternal depression and asthma programs are working with Priority Partners to scale their model to more sites, including East Baltimore Medical Center. Plans include integrating aspects of the CHW pilot activities into other programs.

Previously, the sickle cell program only had access to adult psychiatric services for their pediatric patients. Moving forward, this program will involve child and adolescent psychologists to expand age-appropriate mental health support. Stronger links with pediatric rehabilitation and pain services are also being established.

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> Megan Tschudy, MD, MPH, Medical Director, Harriet Lane Clinic, Johns Hopkins Children's Center

Building on early demonstrated positive outcomes, all three programs are focused on gathering more data to clarify early findings and evaluate continued developments. This will help analyze patient health quality improvements and program costs.

As the COVID-19 pandemic continues, next-step planning carries even more uncertainty than usual. However, the programs are ready to return to helping patients and families better through the personal involvement and guidance of CHWs. "In the clinic, we can improve health in many ways, but health is mostly determined by what happens in homes, schools, and the community," Tschudy says.

Author Robin Warshaw is an award-winning writer who focuses on medicine, social issues, and health care.

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