Case Study: Urgent Medical Care for Asylum-Seeking Infant at US-Mexico Border

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ABSTRACT:
A 22-month-old male presented at a triage facility within an immigration shelter with wounds, inflammation, and swelling across legs and arms; bloody and pus-filled discharge; skin discoloration, scaling, and swelling; and significant pain. His family had been released from immigration detention after migrating from Central America to the U.S. southern border. The attending triage nurse-midwife immediately transferred the patient to a local hospital for emergency care, in addition to signing the patient's family into Specialty Care Action Network (SCAN), a pediatric component of Health Network, a virtual system for medical care coordination. After transfer to another hospital for higher level care, where he received a diagnosis of Carvajal syndrome, the patient was sufficiently stable for transport to a hospital in California, his family's final destination. The resident physician in San Antonio, a SCAN case manager, a network of clinicians, and the medical director in California arranged for his extensive and diverse subspecialty care, through nonprofit funding and charity care in the absence of case management or care for migrants provided by federal immigration and/or health systems.

1. Case Presentation

A 22-month-old boy arrived at a nonprofit immigration shelter with his mother, father, and older brother upon release from an immigration detention center operated by the United States Customs and Border Protection (CBP). The shelter often acts as a transitional space for asylum seekers after release from detention, allowing them to contact family and friends, shower, eat a warm meal, and arrange for transport to their destination within the U.S. This particular shelter has an established triage system for pregnant people and children to assess wellness before travel, which is not typical among U.S. border immigration shelters. At the shelter, child asylum seekers with an acute health condition are enrolled into two programs operated by Migrant Clinicians Network, a national nonprofit focused on migrant health: 1) Health Network (HN), a virtual case management system; and 2) the Specialty Care Access Network (SCAN), an adjunct program of HN that utilizes a national network of volunteer pediatricians and pediatric specialists called SCAN Champions to assist in care coordination and charity care in or near the patient's receiving community.

The patient's condition upon arrival was serious. He was physically inconsolable and unable to support his weight. His legs and feet, and portions of his arms and hands were described by the triage clinician, a nurse-midwife, as "shocking," noting that the skin was "reptile-like." She noted wounds, inflammation, and swelling across legs and arms; bloody and pus-filled discharge; skin discoloration, scaling, and swelling. The family disclosed that in detention, the patient was taken to a hospital at the U.S.-Mexico border, but the hospital discharged the patient back to the detention center reportedly without treatment. Upon return to the detention center, the patient and his family were processed and released to the immigration shelter, which immediately determined the patient needed emergency attention. The child was enrolled in SCAN and then transported by ambulance to a regional children's hospital.

The patient was quickly transferred from the regional hospital to University Hospital in San Antonio, Texas, a teaching hospital affiliated with University of Texas Health Science Center (UTHSC) for a higher level of care. At intake, the patient showed significant skin sloughing, erythrodermatitis, pruritus, and recurrent infections. In addition, the patient's clinicians noted cardiomyopathy, heart failure, esophagitis with gastritis, low bone density, and elevated fecal calprotectin. He was experiencing constipation and occasional diarrhea, had fat in the stool, and had allergies to soy and lactose. He had a tracheostomy, and was underweight due to inadequate caloric intake as well as showing significant growth delay. Additionally, he was found to have multiple closed fractures of ribs with routine healing. His parents disclosed that clinicians in Mexico, during the course of their migration,

had given him a diagnosis of severe dermatitis, multiple allergies, and metabolic wasting (SAM) syndrome, but clinicians in San Antonio were unsure of the diagnosis.

He remained in serious condition for approximately six weeks. The attending physician reported the patient's condition as highly variable, with multiple periods of sepsis and continual efforts to determine a suitable high-calorie diet. During his time at University Hospital, the patient was seen by subspecialists including: infectious disease, dermatology, cardiology, genetics, and nutrition.

At the University Hospital, the patient received the corrected diagnosis of Carvajal Syndrome, a genetic condition with symptoms that begin in early childhood characterized by dilated cardiomyopathy with left ventricular dilation, patchy palmoplantar hyperkeratosis, typically affecting only palms and soles, and woolly hair.[1] Fewer than 1000 people in the U.S. have this syndrome.

To begin his case management in anticipation of his eventual move out of the hospital, SCAN case managers reached out immediately to the patient's family and to their "anchor contacts," people with which the family has regular contact but who are not actively migrating. One day after enrollment at the immigration shelter, a case manager received a text message from the patient's mother, who confirmed that the family wished to migrate to the Los Angeles region to join family, once the patient was stable. The mother informed the case manager that the patient had already been transferred to the University Hospital in San Antonio.

Three days later, after discussion with Health Network's medical team, the case manager reached out to John Harlow, MD, who is a SCAN Champion and the co-founder and medical director of La Laterna, an interdisciplinary co-located clinic that provides holistic care for children and families who have experienced trauma during migration. La Laterna provides medical care, mental health care, legal assistance from immigration attorneys, and case management in one clinic in Los Angeles. Six days later, SCAN case managers had received the first set of medical records from the University Hospital in preparation for the patient's eventual transfer to Children's Hospital Los Angeles, a part of the AltaMed community health center system, under the care and direction of Dr. Harlow and La Laterna.

When Dr. Harlow was informed of the complex medical situation of the patient, he worked with his team to prepare to enroll the patient in emergency Medi-Cal, California's Medicaid health care program, upon his arrival to California, and alert the cardiology and dermatology subspecialties at Children's Hospital Los Angeles to ensure referrals go quickly once he arrived. Because of the patient's condition, travel to California was delayed by almost six weeks until he was deemed safe for discharge and transport.

Upon discharge in San Antonio, the family immediately took the patient to California. The initial intention was to enroll the patient at the intake clinic, but his condition worsened, and the patient was immediately taken to the hospital. At Children's Hospital, the patient received emergency Medi-Cal and was quickly seen over the course of the following weeks by clinicians in cardiology, endocrinology, dermatology, allergy, and immunology, as well as a cardiologic nutritionist, ENT doctor, and palliative care. Despite extensive care, the patient's clinical state remained dynamic; he has been discharged and readmitted to the hospital on multiple occasions, and continues to need close follow-up.

In the meantime, the SCAN case manager has maintained regular care with the patient's family and clinicians. For example, the family reached out to the SCAN case manager upon receipt of a bill from the University Hospital that they weren't expecting. The SCAN case manager connected the family to a case manager at the University Hospital and continues to follow up with the patient's family until the family alerts the case manager that the bill issue has been sufficiently settled.

2. Discussion

Migrant children with acute medical conditions encounter numerous obstacles to accessing and maintaining care, particularly the hard-to-find and expensive pediatric subspecialty care. Consequently, their families frequently

struggle to manage their conditions at every step of their migration, including after migration in their receiving communities around the United States. There is limited literature on the need for and acquisition of medical care during migration within the U.S., in part because the act of migration itself is a barrier to participation in research. However, a growing number of pediatric care providers are identifying and responding to the accelerating need among immigrant children to receive essential health care services. For example, in 2019, the American Academy of Pediatrics issued a Policy Statement on the Organizational Principals to Guide and Define the Child Health Care System and/or Improve the Health of All Children, titled Providing Care for Children in Immigrant Families.[2]

Migrant Clinicians Network, a national nonprofit, initially developed Health Network in response to reports from clinicians at community health centers that migrating patients were unable to continue care, noting a lack of communication between points of health care provision, that led to gaps in medication and repeat testing and diagnoses. HN enables continuity of care. A migrating patient enrolled in HN receives virtual case management, including establishment of primary care with a local health center; culturally responsive support of and communication with the patient and, in the case of children, the patient's family; medical records transfer between points of care; and assistance in identifying and attaining services like sliding scale fees, local assistance programs, and transportation to medical appointments.

Migrant Clinicians Network, along with partners Texas Children's Hospital/Baylor College of Medicine, Stanford University School of Medicine, and University of Texas Rio Grande Valley School of Medicine, expanded HN by forming the Specialty Care Access Network (SCAN) in 2020 in recognition that primary care clinics including community health centers were often unequipped to serve the subspecialty care needs of children asylum seekers. SCAN augments HN's virtual case management by utilizing a network of pediatric subspecialists called SCAN Champions, who assist in identifying sources and coordination of specialty care in conjunction with Health Network's coordination of primary care and establishment of medical home.

When a patient is enrolled in SCAN, the patient receives HN's virtual case management. Additionally, the HN case manager contacts SCAN Champions in or near the patient's receiving community for assistance in obtaining charity subspecialty care, and, once a path to care is identified, arranges for records transfer and other coordinating support to fluidly transfer the child to care.

A federally funded system of care for migrants including asylum seekers is lacking. Unlike refugees, asylum seekers are released into the U.S. without a status that affords them entry into a health system. Statewide health system eligibility for asylum seekers varies widely.[3] Some states require proof of long-term residency before an asylum seeker can attain health insurance; other states have emergency enrollment or fewer obstacles to enrollment to ensure that new arrivals can access state insurance marketplaces. In states where asylum seekers are eligible for health insurance, barriers like language, cost, transportation, and fear may dissuade an asylum seeking family from securing care.

In the absence of a federal case management and a pediatric subspecialty system of care, SCAN is funded through a combination of private gifts, small governmental program funds and volunteer services. With its limited funding, SCAN cared for 80 children in 2023, a small fraction of the number of children with specialty needs from asylum-seeking families that arrived that year. SCAN and HN are available at just one immigration shelter out of more than a dozen along the U.S.-Mexico border. Had the patient chronicled in this case study been released to a different immigration shelter that did not have a relationship with Migrant Clinicians Network, he would not have received any case management or connection to pediatric subspecialty care.

Policy recommendations

All U.S. federal government, private, and community-based organizations involved with immigrant children should adopt policies that protect and prioritize their health, well-being, and safety, and should consider children's best interests in all decisions by government and private actors.

Federal health care systems for asylum seekers must provide post-detention case management to connect asylum seekers with ongoing health conditions to primary care. Additionally, medically fragile asylum seekers with subspecialty care needs require a higher level of case management and connection to subspecialists.

References

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