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Case report

Accompanying indigenous Maya patients with complex medical needs: A patient navigation system in rural Guatemala

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1. Background – rural health care access

Approximately half of the world's population lives in rural and remote areas with poor access to health care.[1] Rural areas face poor penetration by public health systems, shortages of trained health care providers, and geographic isolation from existing health care infrastructure.[1] As the burden of non-communicable diseases in low- and middle-income countries grows,[2] an increasing proportion of the rural population will require access to longitudinal specialized health services available only in urban areas.

Access is a key pillar of global health delivery, which has been defined as the "effective provision of services to people with diseases for which proven therapies exist".[3] This case study examines a patient navigation program as one mechanism for improving health care access for rural patients. Patient navigation refers to a strategy based on offering patients psychosocial support and links to clinical resources and staff throughout the trajectory of an illness. The concept is popular in longitudinal oncological care in high-income settings.[4] Non-governmental organizations such as Partners In Health and Possible have used accompaniment strategies to address client-side barriers to therapy in low-income settings.[5–7] Herein, we describe a patient navigation program developed by [Organization] that builds on the former organizations' strategies of global health care delivery. Our model is designed to overcome barriers to specialty care faced by rural indigenous Maya patients with complex health care needs in Guatemala, and emphasizes patient navigators' roles in facilitating care within government hospitals by surmounting barriers related to institutional bureaucracy.

2. Site description and organizational context

Guatemala is a Central American country with large rural and indigenous populations. Approximately 55% of the population inhabits rural areas, and the country has 23 distinct indigenous ethnic groups, the majority of which are Maya and comprise 45% of the overall population.[8] The Maya population in Guatemala has been politically and economically marginalized due to centuries of Spanish colonialism and a more recent civil war and state-sponsored genocide of Maya people from 1960 to 1996. Seventy-nine percent of Maya people live in poverty,[9] in comparison to the national poverty rate of 56%.[10] Maya people are also more likely than non-indigenous Guatemalans of mixed descent to live in rural areas with limited access to health care.[8]

The Guatemalan constitution guarantees free government-sponsored health care to all citizens through a network of public clinics and hospitals operated by the Ministry of Health.[11,12] This mandate includes coverage of primary and preventive services offered in public clinics or health centers and the provision of inpatient and tertiary care in public hospitals.[11] However, the rural poor have limited access to government health care. Facilities and staff are concentrated in urban areas; seventy-one percent of physicians practice in Guatemala City, where only approximately one-fifth of the population lives.[13] Public health centers and hospitals face chronic budget shortages and corruption leading to frequent medication stock-outs, personnel strikes, and absenteeism.[14] Furthermore, a government program that expanded health care coverage into rural areas for two decades (Program for the Expansion of Coverage, 1996–2015) was recently suspended due to financial constraints, leaving more than 4 million rural Guatemalans without health care coverage.[14] In this context, the majority (83%) of health-related expenditures in Guatemala is financed by households out-of-pocket.[14] Examples of these expenditures include purchase of medications from pharmacies and laboratory tests prescribed but unavailable at government facilities, as well as costs associated with visits to private physicians.[15]

Importantly, there is no functional referral system between primary clinics, whether rural or urban, and the specialty hospitals in the capital

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Table 1
Common conditions treated in Complex Care Program.

Chronic, non-communicable diseases
Diabetes
Cancer
Seizure disorders
Rheumatoid arthritis
Pediatric genetic and developmental disorders
End-stage renal disease
End of life (palliative) care
Acute care or discrete interventions
Pediatric cardiovascular disease
Obstetric emergencies_
Gynecologic conditions
Adult and pediatric surgical conditions
Ophthalmologic care
Acute child malnutrition
Amputee services

that offer services unavailable elsewhere in the country, such as nephrology, cardiology, and oncology. There are no formal mechanisms for tracking or transporting patients between primary health care and tertiary or specialty care settings.[14] As a result, Maya people referred from rural health clinics to higher-level follow-up care must navigate the referral process—including transportation, financing, and coordination of follow-up appointments—alone.[15,16] Typically, they face many economic, linguistic, cultural, and institutional barriers to care, including discrimination, that impede follow-up, as detailed in the next section.[15,16]

In this context, a patient navigation program was developed through [Organization], a non-governmental organization that provides free comprehensive health care services in locally-spoken Mayan languages in rural indigenous communities of Guatemala. [Organization] works in over twenty rural Kaqchikel and K'iche' Maya communities and maintains an annual patient census of 20,000. We began a Complex Care Program in 2009 that supports patients with a variety of conditions requiring specialty care (see Table 1). Examples include patients with cancer requiring chemotherapy and radiation, end-stage renal disease requiring dialysis, and children with cardiac abnormalities requiring surgery. These services are available at specialty hospitals in Guatemala City. All the specialty hospitals we refer to herein are operated through the Ministry of Health, with the exception of the referral oncology hospital, which is operated by a non-governmental organization as a public-private partnership and uses a fee-for-service model. Our Complex Care Program employs patient navigators who accompany rural patients through follow-up appointments to ensure continuity and quality of care.

3. Problems

Our patients face geographic, economic, linguistic, and institutional barriers while navigating referrals, which we detail below and highlight in cases from three patients who have provided informed consent. Though some scholars highlight the cultural barriers that Maya patients face in biomedical settings due to alternate explanatory models of illness and therapeutic expectations,[17–19] we do not focus on this topic herein. In our experience, indigenous Maya patients with complex health needs actively seek biomedical therapies and are foremost overwhelmed by the barriers described below.

3.1. Geographic barrier

The majority of our patients lives in rural hamlets on mountains or plantations without regular public transportation. Travel to government hospitals in department capitals and Guatemala City can take several hours to days, often by a combination of walking and multiple connections on public transportation. Thus, attending one appointment can involve three to four days of roundtrip travel. Traveling to Guatemala City can be a stressful task for rural individuals unfamiliar with public bus lines and landmarks of the notoriously dangerous metropolis. Furthermore, because laboratory and imaging services tend to be unavailable within a single clinical facility, patients are usually asked to obtain lab work and radiologic studies at outside institutions, requiring added travel and city navigation.

3.2. Economic barriers

While government-sponsored health care is technically free of charge, many facilities lack basic supplies and medications, as well as laboratory and imaging services. Typically, patients must visit private pharmacies and medical facilities to purchase these items and tests at their own expense, as prerequisites for their next appointments. This problem is especially noteworthy for patients at the referral oncology hospital, where patients must pay out-of-pocket for chemotherapy and radiation. On top of costs of transportation, lodging, and medical bills, patients incur indirect costs from wage and job loss associated with travel. Additionally, given the limitations of the public sphere, patients with complex needs frequently seek alternatives in the private health system where they are vulnerable to financial exploitation.[15,20]

3.3. Language and literacy barriers

Although Spanish is the official and colonial language of Guatemala, twenty-three indigenous languages are spoken in Guatemala.[21] Approximately 40% of Guatemalans speak an indigenous language.[9] Many patients of [Organization] are monolingual speakers of Kaqchikel or K'iche' Mayan and do not have Spanish fluency or literacy. We have documented strong preferences among our patients for use of Mayan languages in clinical encounters.[22,23] However, clinical care in Guatemala occurs in Spanish, and no professional interpretation services are available through the public health system. Patients may resort to bringing younger family members with some Spanish skills to appointments, but communication between providers and patients in this setting tends to be poor.

Patients are often illiterate and unable to follow signs between hospital departments or fill out paperwork in Spanish. Additionally, public health facilities lack reliable medical records systems and formal systems for sharing records between facilities. Patients must therefore keep track of their own lab work, imaging, and referral letters, and bring these papers to repeated appointments. Many of our patients, who have little formal education, find it difficult to remember which documents to bring to each visit.

3.4. Institutional bureaucracy and discrimination

Administrative systems and staff in healthcare institutions can pose a formidable barrier to rural indigenous patients. Hospitals' administrative rules are usually unknown to patients. For example, the oncology referral hospital accepts only 40 new patients per day, making it essential for first-time patients to arrive early and be among the first in line of a large crowd in order to obtain an appointment. Patients unaware of these rules may arrive to Guatemala City too late to be seen, requiring that they stay overnight in the capital if they wish to try again the next day.

Indigenous patients, particularly those who wear traditional woven clothing or who do not speak Spanish, may face discrimination from hospital staff who are largely non-indigenous. Some of our patients report that despite having appointments, security guards, secretaries, and nurses have turned them away. This sometimes occurs when patients fail to bring required documentation to the hospital, such as their appointment card, medical records, or a particular set of lab tests that may or may not be clinically relevant to their appointment that day. However, in some cases, indigenous patients are turned away despite