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A Patient Navigation System to Minimize Barriers for Peritoneal Dialysis in Rural, Low-Resource Settings: Case Study From Guatemala

To the Editor: As a recent editorial advocates,[1] there is an urgent need to scale-up peritoneal dialysis in rural areas of low- and middle-income countries (LMICs). In this letter, we describe our experiences providing patient navigation and primary care coordination services for people receiving continuous ambulatory peritoneal dialysis (CAPD) in rural Guatemala. We write from the perspective of a nongovernmental health organization (NGO) that has supported rural Guatemalan patients carrying out CAPD for more than a decade.

BACKGROUND: CHRONIC KIDNEY DISEASE IN GUATEMALA

Guatemala is a lower- to middle-income, Latin American nation with a population of 16 million people and a growing need for rural dialysis services due to a confluence of factors. First, although the epidemiology and risk factors for chronic kidney disease (CKD) in Guatemala are not well understood, there is evidence that CKD mortality is among the highest in the Americas.[2] The emerging entity "chronic kidney disease of nontraditional causes" may be a CKD risk factor in rural Guatemala,[3] and regional data show that diabetic renal disease is a significant driver of population mortality.[4] Second, approximately 40% of the population are rural indigenous Maya,[5] a group that faces significant socioeconomic, geographic, and language barriers in accessing specialty nephrology care that is available only in urban tertiary centers.[6] Finally, Guatemala's population is growing and aging rapidly, greatly increasing the absolute number of people at risk for CKD.[7]

Rural Peritoneal Dialysis in Guatemala

Nephrology care for rural Guatemalan adult patients with end-stage renal disease (ESRD), including dialysis, is primarily delivered by the National Center for Chronic Renal Disease (UNAERC). UNAERC is a public institution in Guatemala City that is legally tasked with making dialysis available to citizens.[8] However, UNAERC has had challenges, as its funding increases have not kept up with a rapidly growing dialysis caseload.[9] From a volume of fewer than 2000 persons receiving dialysis in 2008, UNAERC's census had increased to 4286 total dialysis patients as of August 2016; of these, 2710 patients were enrolled in its continuous ambulatory peritoneal dialysis (CAPD) program.[10] Per population, UNAERC's volume helps to give Guatemala 1 of the highest peritoneal dialysis prevalence rates in Latin America and globally.[11,12] The UNAERC staff, although skilled and dedicated, are overburdened by patient volume and frustrated by frequent delays in payment of their wages.[13] In addition, UNAERC has been subject to allegations of corruption.[14]

Care received at UNAERC is technically free of charge, with CAPD supplies delivered to rural homes

throughout the country. Nonetheless, barriers still exist, and UNAERC's dialysis enrollment rates tend to be much lower in rural highland areas with predominantly Maya indigenous populations.[3] For example, UNAERC patients must purchase out-of-pocket all essential dialysis-related medications such as erythropoietin, iron, calcium, and antihypertensive agents, the costs of which can total more than patients' yearly incomes.[13] CAPD patients even from remote areas in Guatemala must travel regularly to the capital city for clinic visits or risk that dialysis supplies will be withheld; each trip might require a day or more of travel time and cost several days' wages. Finally, one-fourth of Guatemalans are monolingual in an indigenous language,[5] and care at UNAERC is delivered exclusively in Spanish.

SUPPORTING CAPD IN RURAL GUATEMALA THROUGH PATIENT NAVIGATION AND PRIMARY CARE COORDINATION

The authors of this letter are staff at Wuqu' Kawoq, an NGO that is dedicated to providing health services for Mayan patients in rural Guatemala. In collaboration with UNAERC, we have supported approximately 25 rural patients carrying out CAPD in 4 different departments since 2007.

Our role in the care of CAPD patients is to attenuate barriers experienced at UNAERC by providing patient navigation services and coordinating primary care (Table 1). CAPD patients are enrolled in our organization's Complex Care Program, which gives them access to our team of patient navigators whose role combines social work, case management, interpretation, patient advocacy, and logistical coordination. Patient navigators arrange transportation from rural areas to the capital city, accompany patients to their UNAERC appointment, interpret between Mayan languages and Spanish, ensure that laboratory results and documents are in order, and advocate for patients during appointments.[15] Elements of this program were adapted from patient navigation interventions to reduce cancer disparities in high-income settings[16] and from accompaniment models of global health popularized by NGOs, such as Partners In Health.[17]

Although CAPD patients generally visit UNAERC once every other month, our medical staff is involved in day-to-day care in a role analogous to that of primary care providers. We treat underlying diseases such as diabetes and hypertension, monitor for clinical and laboratory complications of CKD that arise between UNAERC visits, and manage any non–CKD-related health concerns in patients' home villages. Patient navigators make frequent home visits or telephone calls to check in with CAPD patients, who also have access to our organization's 24-hours-a-day, 7-days-a-week nursing hotline if questions arise such as concerns of peritonitis. We offer all of these services, including the provision of medicines and laboratory tests prescribed by UNAERC, free of charge. We also fund the construction of sterile dialysis rooms in patients' homes, which, although not a direct medical cost, is an integral component of patient safety. To date, we have experienced only 1 episode of iatrogenic peritonitis among our CAPD cohort.

Financing these services is a major challenge, given that CAPD patient navigation is very expensive compared to other global health interventions, and that there is limited international funding available for noncommunicable diseases. Such funding challenges prohibit us from accepting all rural ESRD patients who wish to enter our program. We budget $1800 per patient per year for new CAPD starts and approximately $500 per patient per year for ongoing cases, although this latter figure varies significantly based on an individual's underlying comorbidities. We are unable to supply i.v. iron, calcitriol, or non–calcium-containing

Table 1. Challenges, opportunities, and solutions for support of peritoneal dialysis in rural Guatemala

Challenges	Opportunities	Solutions
Language and literacy barriers to specialty nephrology care for indigenous Maya population	Rising number of bilingual Maya indigenous social workers experienced in issues related to health advocacy Low cost of labor in Guatemala	Recruit professional Maya social workers to serve as patient navigators
Patients live in rural, difficult-to-access settings	Extensive, reliable cellular network coverage High mobile telephone penetration throughout country	Bulk of care coordination and care monitoring provided via telephone encounters
High cost of ESRD medications such as erythropoietin, i.v. iron, and calcitriol	Robust generic pharmaceutical industry in Guatemala	Institutional formulary limited to generic drugs Substitutions as feasible to reduce costs
Patients present late in CKD course, often with irreversible renal damage	High-quality nephrology care, including CAPD management, available in capital city	Patient navigators coordinate transportation and provide accompaniment to link rural communities and urban referral centers
Supporting CAPD is expensive and requires long-term commitments to patients	Blended financing models are emerging in global health	Cross-training of primary care staff allows for coverage of core salary obligations from general operating funds Crowdfunding provides funding for initial investment in care Grants permit exploration of new areas of programmatic innovation

This table is adapted from Flood D, Mux S, Martinez B, et al. Implementation and outcomes of a comprehensive type 2 diabetes program in rural Guatemala. *PLoS One.* 2016;11:e0161152.[23] CAPD, continuous ambulatory peritoneal dialysis; CKD, chronic kidney disease; ESRD, end-stage renal disease.