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MEDICAL EDUCATION

Best Practices for Teaching Care Management of Undocumented Patients

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Abstract

Different standards of care for undocumented Latino patients raises ethical questions for teachers and learners. This lack of parity can cause moral distress for both and prompts consideration of whether decisions made on a patient's behalf are ethical. Teaching advocacy and creating projects and partnerships to improve access and quality of care for this vulnerable population can help fight burnout and improve health outcomes.

Care for Undocumented Immigrants in Philadelphia

Over 11 million undocumented persons are living in the United States.¹ Approximately 50 000 of them are living and working in Philadelphia.² Given the surge of Latinos in this country, many in academic medicine have opportunities to supervise and teach students and residents working with this vulnerable population.

Puentes de Salud clinic in Philadelphia is a low-cost clinic designed for the care of undocumented patients and has been in existence for 11 years. The clinic serves primarily Latinos, mostly from Mexico and Central America, who are employed in physically demanding and sometimes dangerous jobs such as construction, landscaping, factory work, and restaurant work.³ To date, 6500 patients have been served by Puentes. Although the clinic is a nonprofit, it shares close ties with several Philadelphia academic institutions. The clinic teaches internal medicine and family medicine students and residents, nurse practitioner students and residents, and nurses. In this brief paper, I will describe ethical, clinical, and pedagogical challenges encountered by trainees when providing medical care to undocumented Latinos.

Ethical Challenges in the Care of Undocumented Latinos

Our students and residents are working in some of the most well-resourced hospitals, where patients receive incredibly complex and novel treatments. A quick bus ride across town places learners in an entirely different clinical environment, where health care professionals cannot order off a menu of services and offer comprehensive medical care for little additional cost to the patient. These inequities manifest in various ways and affect both patients and clinicians.

Different standards of care. First, our residents and students are exposed to inequity through different standards of care for this population. Puentes is mostly staffed by volunteers, residents, and a few core clinicians, so patients often do not receive follow-up phone calls about lab results or continuity with a clinician. In addition, patients cannot get urgent specialty care or low-cost or advanced diagnostics.

Clinically, we practice and teach differently at Puentes than at our home institution due to financial and access issues for patients. For example, due to cost, we may start a certain blood pressure medication preferentially rather than first checking a urine protein, which is the standard of care. We may use a less potent cholesterol drug due to price or treat empirically for a stomach infection with extensive antibiotics costing \$60 without ordering the \$125 definitive test first. Our patients trust us to make the best decision on their behalf, and cost weighs heavily in the risk-benefit tradeoff as all of our patients lack insurance. Shared decision making is challenging, as patients usually ask us to make decisions on their behalf. The clinician is thus in an impossible situation—can we justify asking patients to pay \$20 per month for the "gold standard" cholesterol medication rather than \$4 per month for the less powerful alternative? Will that small increment of lipid treatment really prevent a true cardiac event? Is it worth the \$190 per year that the patient could save to feed his or her children or send home to family in Mexico or Central America? As we make these decisions in the patient's best interest, the nagging question remains: Are we propagating a hidden curriculum that teaches that substandard care is good enough?

Lack of access to medical care and moral distress. It is often shocking for learners to discover that undocumented patients cannot get the surgeries, diagnostics, and specialty care that are routine in academic medical practices. Sadly, patients also come to Puentes with the expectation of a full offering of medical services. We meet countless patients seeking treatment for chronic conditions such as severe hernias, advanced arthritis, disfiguring lipomas, chronic ear infections, sinus infections, severe uterine fibroids, and joint deformities, to name a few. It is morally distressing for practitioners and learners alike to tell patients that quality of life surgeries cannot be paid for.

Perhaps even more ethically challenging than the inability to refer patients for surgery is the absolute denial of <u>organ transplantation</u> to patients in Pennsylvania and throughout the United States. We are treating several cases of alcoholism, especially in men. We care for at least 5 patients with end stage liver disease from alcohol, ranging from age 26 to 52. They are out of options for treatment. I can remember the night when I met the first of these patients. I was accompanied by one of my favorite medical students, and I told the patient that he would die if he kept drinking and that he cannot get a new liver here in the United States, and certainly not in Mexico. The student suddenly left the room. After the visit, I found the student weeping in an empty exam room. He could not believe that this patient and all undocumented persons in this country are not eligible for

organ transplantation. We now have a patient who is on <u>dialysis</u> with no hope for a kidney transplant and another young woman days away from dialysis. Given the high prevalence of diabetes and end-stage renal disease in Latinos,^{4,5} millions of undocumented Latino immigrants are marching toward dialysis with no hope for a transplant that would allow them to continue to lead productive work lives and support their families. Medicare spends on average \$88,000 per year on dialysis per patient, when a transplant would cost considerably less (about \$33,000).⁶

Seeing these disparities in care can create deep <u>moral distress</u> for clinicians and learners. We need to balance the acceptance of what is not feasible with providing the best care possible to these vulnerable patients. Structured teaching and advocacy would help fight burnout and contribute to advancing the care of the undocumented population by avoiding complacency and moral defeat.

Teaching Points for Learners Working With Undocumented Latinos

Understanding social determinants of health and unique health issues. Learners must first understand the unique social determinants of health for undocumented patients. Our patients are often working 60-hour weeks and living with overwhelming toxic stress due to their undocumented status. Patients can experience severe trauma crossing the border but then experience further trauma living in the United States, such as fear of deportation, financial stress, discrimination, language barriers, and stigma. Patients divulge to us additional stressors, including deep depression and anxiety from family separation and sexual violence. As mentioned previously, there is a concerning rate of alcoholism in our population, leading to devastating health outcomes. Learners should be taught to ask specifically about a patient's occupation, hours spent working, living situation, family structure in the United States and abroad, journey to the United States, depression, and substance use. Often this history can illuminate the true threats to health.

Navigating the medical system for patients with complex health care needs. Clinicians can address their moral distress by leveraging the resources that they do have to provide the best care possible for undocumented patients. We teach residents how to apply for Emergency Medical Assistance (EMA), which provides 5 months of health insurance for patients in crisis with an organ-threatening or life-threatening condition. Learners are taught to identify eligible patients, write a medical letter of necessity, and complete the application. EMA also covers hospital admissions for serious medical conditions. As such, we teach learners to use the emergency room as a point of admission for undocumented patients with a concerning medical condition. Our clinicians call the emergency room directly to ensure that the patient is admitted for a full workup rather than a "treat and street" encounter. This sort of care and communication is made possible by our academic partnerships. We have had some wonderful wins. We diagnosed a young man with autoimmune hepatitis through an admission and liver biopsy. He now has completely

recovered, has normal liver function, and is off his immunosuppression. Another very young man with a family history of Lynch syndrome was admitted with severe iron deficiency anemia and abdominal pain. He was found to have a large colon cancer on a Friday and had a hemicolectomy with successful removal of the cancer on the following Monday. These sorts of emergency situations do not cause additional financial distress for our patients, as the admission or emergency visit is almost always covered through EMA. For those patients not needing emergency care but for whom specialty care, diagnostics, and monitoring are needed, we teach learners to guide these patients to city clinics, which provide low-cost care and referrals for any resident of Philadelphia.⁹

Connecting to community resources. In addition to understanding how to navigate the medical system, learners should be taught advocacy. For example, when patients are denied EMA, learners should be taught how to advocate for these patients through writing a letter of appeal and contacting a lawyer. As physicians, we are ill equipped to address workplace discrimination or injury, deportation fears, or asylum evaluations. Lawyers are vital for our patients. In every major city, there are immigration lawyers and immigration advocacy groups. Medical professionals caring for undocumented patients should become familiar with these groups and contact these partners for help. At Puentes, we are lucky enough to have a medical-legal partnership with Justice at Work in Philadelphia, which provides our patients with onsite legal services.

Learner-driven quality improvement projects. After gaining understanding of the myriad challenges facing undocumented populations, learners can create projects to address inequity and quality improvement. Such efforts both improve patient care and, in my experience, combat burnout, as learners feel that they are engendering positive change. For example, the author and collaborators currently have a grant funded by Penn Presbyterian Medical Center to provide free fecal immunochemical testing (FIT) for colorectal cancer screening and have negotiated a low-cost fixed price for colonoscopy. This community-academic collaboration to provide care is truly novel and exciting and will hopefully be just the beginning of more partnerships to provide further access to care for undocumented patients in Philadelphia.

Cultural humility. Puentes de Salud offers learners the opportunity to practice in a multidisciplinary team and to subvert the paradigm of physician as leader. Nurse practitioners provide vital continuity of care, and community health workers, or promotoras de salud, are key partners in the health of our population. The promotoras have all received training through the DPP Group Lifestyle Balance™ (GLB) Program¹0 and can counsel patients with diabetes and obesity in a much more effective way than most clinicians due to their specialized and culturally appropriate training. In my experience, over half of patients referred to promotoras control their severe diabetes with just diet and oral medication, and data show that promotoras help patients reduce the risk of developing diabetes.¹¹ I advise learners to fight the urge to always treat uncontrolled

diabetes with insulin: this population is different. Our patients have risked so much to get to this country and have incredible resilience and investment in their own health. Patients' self-efficacy combined with culturally appropriate teaching yields incredible results.

Philadelphia is reflective of many other cities in the United States. The 11 million undocumented people aging and developing chronic disease will be sick and will need us. It is our moral imperative as physicians to understand the unique challenges facing this population and to teach our students and trainees to expertly care and advocate for this highly vulnerable population.

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