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Publication Date

2019

DOI

10.1016/j.socscimed.2018.10.024

Peer reviewed



Published in final edited form as:

Soc Sci Med. 2019 January ; 220: 49–55. doi:10.1016/j.socscimed.2018.10.024.

Stratified citizenship, stratified health: Examining latinx legal status in the U.S. healthcare safety net

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Abstract

Our paper explores how legal status stratification shapes the health and health care of low-income patients with chronic illnesses in the U.S. healthcare safety net. Drawing on data from over two years of ethnographic fieldwork at urban safety-net clinics, we examine efforts by Complex Care Management (CCM) teams to stabilize patients with uncontrolled chronic illnesses through primary care-integrated support. We show that stratified citizenship and geographic variability correspond to different possibilities for health care. We suggest an approach to immigration as a structural determinant of health that accounts for the complex, stratified, and changing nature of citizenship status. We also highlight how geographical differences and interactions among local, state, and federal policies support the notion that citizenship is stratified across multiple tiers with distinctive possibilities and constraints for health. While county-based health plans at each of the study sites include residents with varying legal status, lack of formal legal status remains a substantial obstacle to care. Many immigrants are unable to take full advantage of primary and specialty care, resulting in unnecessary morbidity and mortality. In some cases, patients have returned to their country of origin to die. While CCM teams provide an impressive level of support to assist immigrant patients in navigating healthcare and immigration bureaucracies, legal and geographic stratification limit their ability to address broader aspects of these patients' social context.

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Keywords

United States; Immigration status; Social determinants of health; Healthcare systems; Chronic illness; Health inequalities

1. Introduction

The tenuous political situation of immigrants demands attention to the crucial role that legal status plays in shaping health (Derose et al., 2007; Portes et al., 2012; Castañeda et al., 2015; Martinez et al., 2015; Torres and Young, 2016; Philbin et al., 2017). In the United States, health and immigration policy debates have created growing uncertainty in both spheres. Despite the 2010 Patient Protection and Affordable Care Act's (ACA) achievements, undocumented immigrants and many legally present immigrants remain excluded from Medicaid expansion and state insurance exchanges (Jerome-D'Emilia & Suplee 2012; Marrow & Joseph 2015). For immigrants living with chronic illnesses, such exclusions are especially difficult to endure. We explore how legal status stratification compounds existing inequalities, undermining the health of low-income Latinx patients with multiple chronic illnesses. Drawing on data from over two years of ethnography at two urban safety-net clinics, we examine efforts by Complex Care Management (CCM) teams to stabilize patients with uncontrolled chronic illnesses through primary care-integrated support.

We found that interactions among local, state, and federal policies stratified legal status and contributed to patients' health experiences. While county-based health plans at each site provide coverage for undocumented residents, lack of legal status nonetheless exacerbates barriers to care. CCM teams deftly support immigrant patients in navigating healthcare and immigration bureaucracies, but they often cannot overcome broader aspects of these patients' social exclusion. Obstacles include federal ineligibility for employment, General Assistance, and housing support; discrimination experiences; and barriers to advanced treatment for chronic conditions. Health possibilities for immigrant patients are thus stratified relative to their inconsistent standing in local, county, and federal policies.

Previously, we elaborated on structural challenges facing safety-net CCM programs (Fleming et al., 2017; Thompson-Lastad et al., 2017; Van Natta, 2018). Here, we expand on our prior findings, describing how even when immigrant patients engaged with CCM teams, lack of legal status frequently undercut these efforts. This paper specifically highlights: 1) the way in which stratified immigration status differentially impacts health and 2) geography's importance in stratifying citizenship through health institutions. Despite supportive local policies and institutional commitments to serve vulnerable patients in these two safety-net systems, immigrants lacking formal legal status were unable to fully leverage primary and specialty care, resulting in unnecessary morbidity and mortality. In some cases, patients returned to their country of origin to die. Immigrants' healthcare access at study sites was expansive, but structural barriers and federal legislation negatively shaped the health of immigrants we observed.

Our paper begins with an overview of how scholars have approached the central role that legal status plays in determining health and situates our study's contributions within that

literature. We then contextualize immigration policy relative to social benefits provision in the U.S. and the subsequent diminishing legitimacy of immigrants' societal participation. Our ethnographic data then illustrate these processes among undocumented and legally present immigrants. We conclude by calling for scholars and policymakers to think critically about the role of stratified legal status in healthcare systems, which may either subvert or reproduce unequal belonging.

2. Background

Recent scholarship in various disciplines argues for treating (im) migration status as a social determinant of health (Davies et al., 2006; Castañeda, 2009; Quesada et al., 2011; Zimmerman et al., 2011; Castañeda et al., 2015). Doing so positions immigration status as a fundamental cause of health inequalities (Link and Phelan, 1995). Yet, as scholars such as Viruell-Fuentes et al. (2012) and Castañeda et al. (2015) point out, growing literature on immigration as a social determinant of health often focuses on individual responsibility (in the form of behavior and/or “acculturation”) or immigrants' health access – neither of which draws sufficient attention to structural vulnerabilities or the effects of local and national policies and contexts on immigrants' health. Philbin et al. (2017) further argue that scholarship on immigration should pursue a “multi-sectoral, multi-level, and multi-outcome” approach rather than focusing on isolated policies and variables (Philbin et al., 2017, 29). Taken together, these scholars stress that immigration is not merely a proximal determinant of health, nor something affecting individuals' health behaviors by way of culture. Instead, it is a fundamentally important phenomenon in its own right that must be examined as it intersects with other structures and specific policies to shape immigrants' health.

Some scholars have taken up this provocation to conceptualize immigration as a structural determinant of health that intersects perniciously with other forms of social stratification at multiple levels of policy and practice. Asad and Clair (2017) advance the concept of “racialized legal status,” wherein *de jure* citizenship classifications ostensibly unrelated to race have the *de facto* consequence of discrediting racial/ethnic minority groups' social position. They suggest that while Latinx citizens may ostensibly have access to more benefits and greater legal protections than their undocumented counterparts, the spillover effects of being associated ethnically with a racialized, discredited status may compromise their actual access to such benefits and protections.

Further, Wallace and Young (2018) distinguish between *immigration* policies and *immigrant* policies. Whereas the federal government determines laws governing the movement of people across borders, state and local jurisdictions have discretion over the degree to which immigrants are included in social and civic life, for example through local healthcare programs and sanctuary resolutions. Varsanyi (2006), for example, describes how some localities determine social citizenship based on local residence rather than national membership and may elect to extend benefits such as health care on that basis. Yet multilayered policy environments may either temper or exacerbate immigrants' exclusion from social welfare systems. Immigrants who live in states with restrictive immigrant policies and anti-immigrant sentiment experience negative health (White et al., 2014; Morey et al., 2018; Kline, 2017). And even in places with locally inclusive immigrant and

health policies, such as San Francisco (Marrow, 2012) and Boston (Joseph, 2017a; 2017b), safety-net clinics must contend with the restrictive practices of state and federal agencies, such as those administering Medicaid and enforcing federal immigration laws. As Asad and Clair (2017) suggest, and as Watson (2014) and Horton (2016) demonstrate empirically, Medicaid's citizenship restrictions not only bar undocumented immigrants from comprehensive health care, but they also spill over to prevent legally present immigrants and U.S.-born Latinx citizens from using benefits for which they qualify. Much like the patients we discuss below, Horton (2016) highlights how this especially impacts immigrants with end-stage organ failure who require dialysis and/or organ transplant.

Despite scholarly consensus on the salience of legal status for stratifying health, there is insufficient empirical research on the relationship among the structures and practices shaping immigrants' health. Our research addresses this gap by providing timely empirical and granular evidence from two U.S. safety net clinics. Taking seriously Philbin et al.'s (2017) call for more a nuanced and comprehensive approach to immigration as a social determinant of health, we examine multiple sectors and levels influencing diverse immigrant health outcomes. While our commitment to anonymity limits specific description of local policies and programs, our study sites were located in sanctuary jurisdictions in a state with inclusive immigrant policies, where counties provide healthcare coverage to undocumented immigrants based on county residence rather than national citizenship. Through robust ethnographic and interview data, we demonstrate how immigration status affected the lives of chronically ill immigrants, contributing to the burgeoning literature on immigration status as a structural determinant of health. We present evidence from undocumented, legal permanent resident, and naturalized citizen patients with distinct immigration trajectories and emphasize the roles their immigration status and national and local immigration policies played in shaping their health, as well as their unintended consequences. In so doing, we illuminate the opportunities and limits of inclusive subnational policies while showing the social life of policy.

2.1 The national context of immigration policies

Superficially, the exclusion of many non-citizens from the ACA appeared to be a political concession to the bill's conservative opponents. In reality, it signaled a continuation of policies crafted in the mid-1990s, most notably Temporary Assistance to Needy Families, the redesign of welfare. These policies reconfigured the intersection between immigration status and health benefits. The 1996 Personal Responsibility and Work Opportunity Reconciliation Act restricted eligibility for public benefits among citizens and non-citizens alike, establishing two classes of immigrants for benefits purposes: "qualified" and "not qualified." In effect, however, the reforms excluded nearly everyone from most benefits, irrespective of status (Broder et al., 2015).

Welfare reform also coincided with the 1996 Illegal Immigration Reform and Immigrant Responsibility Act barring non-citizens – including many legal permanent residents – from accessing public benefits (De Genova, 2014) and criminalized many aspects of unauthorized immigration previously treated as civil offenses (Fragomen, 1997). These laws, combined with the expansion of federal security agencies following the attacks of September 11th,

have led to skyrocketing detention and deportation rates of both undocumented immigrants and legal permanent residents, while narrowing parameters of legitimate social, economic, and political inclusion among many classes of immigrants (Menjívar, 2006; DeGenova, 2014; Boehm, 2016; Golash-Boza, 2016). Beyond growing institutionalization of this “cimmigration” phenomenon (Stumpf, 2006; García Hernández, 2015), the 2008 economic recession led to increased expression of anti-immigrant sentiment throughout the U.S. (Portes and Rumbaut, 2014).

Understanding the state of contemporary immigration policy is important for grasping how immigration status shapes an individual’s health prospects in the safety net. The purpose of the safety net is care provision for those without insurance and/or those insured through public programs. In many circumstances, non-citizens do not qualify for insurance through the typical channels: employment-based options, subsidized state exchanges, and Medicaid/Medicare. The situation is especially challenging for undocumented or recently arrived immigrants who in most cases are eligible only for emergency and pregnancy-related care (Broder et al., 2015). While the 1986 Emergency Medical Treatment and Active Labor Act (EMTALA) requires that all emergency departments at hospitals receiving federal funds treat any patient experiencing a medical emergency, regardless of immigration status or ability to pay, the law’s definition of “medical emergency” is open to interpretation by individuals and institutions (Sommers, 2013). In places where state or local funding is not provided to enforce EM-TALA, the law mandates immediate stabilization but does not require comprehensive care.

2.2. The local context of immigration policies

Despite increasing exclusion of immigrants from public benefits, some sub-national efforts have encouraged more inclusive forms of social citizenship. Varsanyi et al. (2012) and Gulasekaram and Ramakrishnan (2015) describe this as a function of U.S. immigration federalism, in which states, counties, and municipalities exercise substantial legislative power over immigrants residing within their borders. This occurred in the sites we observed, where both county and statewide health and immigration policies support immigrants despite federal restrictions. Even “unqualified” non-citizens qualify for more services than their counterparts in other counties, including eligibility for county-funded low-income health programs and (in special cases) comprehensive coverage under Medicaid.

As is true throughout the U.S., undocumented immigrants at our study sites who presented with acute or short-term conditions, such as pregnancy or trauma, could receive federally-funded Emergency Medicaid services. For preventive care, chronic illness, and specialty care, however, they relied on county-administered programs lacking citizenship requirements. In the event that undocumented immigrants at our study sites became gravely ill, they could qualify for full-scope Medicaid services paid for with state – not federal – funds. This was reserved for worst-case scenarios because it required undocumented immigrants to disclose their unauthorized presence to a federally-funded agency and aver that federal immigration agencies were aware of their unlawful presence but not actively deporting them. These requirements made applying for full-scope Medicaid risky for patients already contending with serious health challenges.

Distinctions in legal status and geography were vital for the CCM patients we followed. Like all program enrollees, the patients discussed below suffered from multiple chronic illnesses that, in conjunction with arduous social situations, resulted in frequent hospitalizations and emergency department visits. The cases discussed here stood apart from the average safety-net CCM patient, however, because they came from immigrants whose varying legal statuses had differentially shaped their healthcare contexts.

3. Methods

The qualitative data herein come from a broader ongoing study exploring how CCM programs at two urban safety-net sites address their patients' social and medical needs. Our study was not specifically designed to examine immigration issues, but ethnographic observations and semi-structured interviews revealed this as an important theme. As our team has previously reported (Fleming et al., 2017; Thompson-Lastad et al., 2017; Van Natta et al., 2018), these CCM clinics – “Clinic 1” and “Clinic 2” – follow a staffing model of dyadic nurse and health coach teams that collaborate with other primary care providers, nurses, health coaches, and social workers. Both CCM programs enroll patients with multiple chronic co-morbidities who have had at least 3 hospitalizations and/or ED admissions within the past 12 months, although these initial enrollment criteria evolved over the study's course. Each of these programs employs intensive, interdisciplinary care coordination toward reducing hospitalizations and improving illness self-management among enrolled patients, graduating them upon meeting these goals.

Two ethnographers (including one bilingual in English and Spanish) at each site observed patients and providers in the clinic and during home visits and shadowed participants during their day-to-day interactions in order to understand clinic flows and processes. Between January 2015 and January 2018, we conducted over 1000 hours of observations of providers and clinic staff, following their interactions with patients, workflow and communication systems, and problem solving in the CCM context. The ethnographers recorded these observations in detailed fieldnotes, and all participant information and program sites were anonymized. The study site institutions' Institutional Review Boards approved all study procedures.

Ethnographers also conducted 155 semi-structured interviews with 72 patients. Patients were invited to participate in three interviews at 6–12 month intervals and received a \$25 gift card for each interview. Audio recordings of each interview were transcribed and professionally translated if conducted in Spanish. Interviews probed for patients' health goals, engagement with care teams, and challenges in navigating care and achieving disease management. Demographic questionnaires indicated that of these patients, 22 were foreign-born (15 at Clinic 1, 7 at Clinic 2). Several more immigrant patients were observed during ethnographic observations. Some patients who were initially open only to observations opted into interviews after getting to know us through our continued presence alongside CCM staff.

Importantly, we did not ask patients directly about their immigration status in surveys or in-depth interviews; rather, we observed how their status came up during healthcare and social service negotiations. Many patients also spontaneously brought up the issue when discussing

challenges related to their health and wellbeing, such as housing, employment, and Medicaid coverage obstacles. Some were unlawfully present and spoke to us about having to stay under the radar, while others discussed their benefits eligibility in terms that made their status clear. We ascertained that of the 5 cases presented below, three were “undocumented” in that they did not have papers authorizing their presence in the U.S., one had legal permanent residence, and one was a naturalized U.S. citizen. Other patients we interviewed and observed had a similar range of statuses, and some were also attempting to adjust their status or challenge deportation orders. While data from both clinic sites inform our analysis, we focus here on cases from Clinic 1, which had twice as many immigrant participants as Clinic 2.

Semi-structured interviews with providers and CCM-affiliated program staff were conducted in two waves at an interval of about 12 months. These totalled 101 interviews with 52 individuals, including CCM program staff, primary and specialty care providers, social workers, and providers at community-based organizations working with the CCM. Interview content related to providers’ and staff’s interactions with various departments within and beyond their respective institutions, perspectives on CCM program’s goals and impacts, consideration of the different populations that CCM programs serve, processes of patient enrolment and progression in the program, and challenges to providing care.

All transcripts and fieldnotes were coded according to grounded theory principles using ATLAS.ti software. Translated interview transcripts were also analyzed by the team’s bilingual researchers against the original audio files to ensure nothing was lost in translation. Drawing from interview guide items and frequent data review, a team of seven researchers collaboratively and continuously developed codes and sub-codes during data collection. The team then compiled a codebook rooted in the fieldnotes, interview transcripts, and memos of each ethnographer. ATLAS.ti queries of these codes enabled identification of emerging themes and initial substantive analysis of the data. Themes relevant to the present analysis included those concerning legal status, social networks, housing, and care coordination.

4. Findings

The patient stories presented here reflect a range of legal statuses and health outcomes, ordered according to their respective place along the continuum of legal status stratification from “undocumented” to naturalized citizen. By not asking status questions outright, matters of immigration were able to emerge organically without undermining rapport between the research team and immigrant patients. Whether patients were truly “undocumented” (in that their presence in the country was not officially recognized until they fell ill and required intensive healthcare services), legal permanent residents, or naturalized citizens who qualified for a combination of county and federal healthcare and social support programs, these patients had much in common. Most had come to the U.S. to work and had been here for many years before illness derailed their lives. Many also had deep attachments to their local communities and clinics, as well as to their home countries – relationships that were complicated by poor health.

We found that immigrants with some form of legal status fared better than those who did not. While both groups faced extraordinary socio-medical distress, those with legitimate status benefited from more robust social and medical services. Our findings thus illustrate the array of challenges facing immigrant patients even in a region of the U.S. boasting relatively inclusive health and immigration policies. They also highlight how precarious legal status can compound other structural vulnerabilities shared by the low-income, chronically-ill population of CCM patients in the safety net.

“Everyone says, ‘Come back, it’s late.’”

When undocumented patient Eladio (all names are pseudonyms) crossed from Mexico in 2002, he planned to earn some money and return to his family as soon as possible. We met him at a home visit when he first enrolled in CCM and learned that he was from an indigenous community and spoke fair Spanish but no English, and he could neither read nor write. Until he reached middle age, he had no significant health concerns. It was not until needing emergent hospitalization for complications from advanced diabetes – including eye disease and heart and kidney failure – that he realized something was wrong. By the time he enrolled in CCM, Eladio was going blind, had toes amputated, and was nearing dialysis. He was also marginally housed (common among the immigrant patients we observed), rooming with a friend on a bunk bed in a cramped, moldy bedroom. Eladio worked constantly changing hours in a packaging plant and struggled to balance work with medication and appointment regimens.

Diabetes had dealt Eladio an unexpected blow, one intensified by his being separated from family and unable to provide for them. They often wondered when he would return, saying, “Come back, it’s late.” Eladio wanted to return. “I came here to ... move forward,” he said in halting Spanish. “I say I’m going to go [back] sometime and I’ll go. ... I didn’t think how much time now. It’s late.” He then explained that when he was hospitalized one year prior, he awakened to learn that his father had died. Eladio had not seen him since leaving Mexico, and given his declining health and undocumented status, it was impossible for him to return to pay his respects. He cried silently while recounting these experiences.

When Eladio was ill as a child, his mother cared for him by passing coins over his forehead and saying secret words. In the U.S., however, Eladio sensed his health was beyond repair. The impending need for dialysis would make it impossible for him to work the hours necessary for survival. Without work and adequate health, Eladio had no reason to stay in the U.S. Without dialysis, however, death was certain. Although CCM was able to arrange for dialysis through Medicaid, Eladio was ineligible for income or housing support services. He expressed conflicting feelings over whether to return to his family versus his desire to receive treatment.

Some months later, when we attempted to coordinate a follow-up interview with Eladio, his health coach crossed his name off our participant list. Although the team had tried to monitor Eladio closely and engage him in more intensive care that would be covered by county- and state-level programs for undocumented immigrants, his economic, food, and housing situations remained inadequate. The health coach explained that they had been unable to persuade him to choose dialysis over work, and eventually he stopped returning

their calls. They reached out to his friends, but he became lost to follow up. Finally, during an informal memorial ceremony, Eladio's CCM nurse teared up while explaining that he had returned to Mexico to die.

“Well how's he gonna die?”

Unlike Eladio, 52-year-old patient Manuel had left his home country of Nicaragua 30 years ago with no plans to return. He considered himself a political refugee (although there was no indication that the U.S. government had designated him as such), having been told that he would be killed if he ever returned. His situation in the U.S. had also become critical. He was homeless and terminally ill with non-alcohol related liver failure. Because fluid regularly overloaded his abdomen and impeded his breathing, he relied on frequent abdominal taps to remove excess fluid. Initially his medical team considered surgical procedures, including a liver transplant, but they determined that these were unlikely to succeed in view of his rapid deterioration and lack of social support.

When Manuel ran out of treatment options, CCM consulted palliative care specialists for symptom management. His CCM health coach assumed much of the work of navigating the complex immigration and health bureaucracies that would enable such care. She attempted to maximize his care through both the county health plan and by engaging a special provision for gravely ill immigrants to enroll Manuel in state-funded complete Medicaid coverage, but this was difficult because Manuel was homeless and undocumented. The first obstacle was problematic because Manuel had mistakenly written on the application that he lived in a neighboring county not offering comprehensive coverage for undocumented immigrants. (We observed similar situations among undocumented CCM participants at our study sites who lived in vehicles.) Manuel's paperwork needed to accurately document instead that he was homeless in the county where he had been receiving medical care. The health coach worked with the county health plan offices to correct this, enabling Manuel to maximize coverage through that plan.

Manuel's undocumented status was more difficult to overcome. The health coach worked with his physicians to compile dense paperwork confirming that Manuel had under six months to live. This triggered eligibility for what CCM workers called “catastrophic” benefits, some of which which he would not otherwise qualify as an undocumented immigrant, including short-term placement at an extended care facility, financial support through General Assistance, and repatriation to Nicaragua. These benefits corresponded to a vague assemblage of county health plan, charity care, and comprehensive Medicaid resources – the boundaries of which were unclear to CCM workers or our research team. The 1996 welfare and immigration reforms ensured that an attempt to use such benefits could count against a citizenship application if Manuel ever tried to naturalize, but that no longer mattered. Manuel's health coach also sought temporary housing in case the repatriation plan failed. In the end, Manuel elected to “go home” to Nicaragua to die rather than dying alone in a U.S. long-term care facility.

The CCM team accepted this decision, but the logistics troubled them. Once Manuel's catastrophic benefits were secured, CCM worked with palliative care to prepare him for the realities of repatriation – including the journey itself and the absence of medical equipment,

facilities, and pharmaceuticals once he arrived. They gathered what they could to comfort him through the three months he was projected to live. “He needs good drugs,” his CCM nurse said firmly, and the health coach replied that he had received a 3-month supply of morphine to alleviate pain and shortness of breath. “But what about when he runs out?” the nurse asked. “Will he just [discontinue] his [abdominal drain]?” Other team members balked, saying that would be tantamount to drowning. “Well how’s he gonna die?” the nurse asked gravely. She had held onto hope that Manuel could get a transplant through state-funded Medicaid if he stayed in the U.S., and she struggled with the realization that Manuel’s death abroad might be unnecessarily brutal.

Although it is impossible to know what Manuel’s outlook would have been were he a legal resident or U.S. citizen, the intersection of immigration and health logistics created deep anxiety for both Manuel and his care team. They leveraged all resources available and maximized the inclusive local health policies at their disposal. Manuel’s health needs surpassed what the county could provide, however, being no match for inflexible federal barriers to immigrant inclusion. Although Manuel described himself as someone who had fled political persecution, his lacking official refugee status (difficult for Latin Americans to secure) meant that his very presence in the U.S. was illicit and unworthy of comprehensive care. Manuel’s CCM team empathized with his situation, and the sanctuary policies of the county in which he lived supported their work. Additionally, his eligibility for catastrophic benefits provided him with needed immediate services; however they were conditioned upon his certain and imminent death and required repatriation to Nicaragua.

“I’ve almost reached that point.”

Like many CCM patients we observed, Hector’s life as an undocumented immigrant had been relatively stable until he suddenly fell ill. He had been working regularly in construction and earned enough money to buy a car and a house in the county where he lived, about sixty miles from Clinic 1. Diabetes caught Hector off guard, and his zip code exacerbated its negative effects. Unlike the counties of our study sites, the county in which Hector lived offered little healthcare support to undocumented immigrants. Preventive care and programs like CCM were scarce there. When Hector suddenly went blind from diabetes, he could no longer work. He fell out with the people with whom he lived, claiming that they evicted him from his own home. He was left blind, unemployed, and living in his car. He depended on public transportation, and occasionally friends and acquaintances, to get to medical appointments at our study site, where he used a local address to qualify for services. He frequently missed appointments when having to use public transit to travel long distances to the clinic.

The CCM team knew this arrangement was suboptimal and jeopardized Hector’s health. They also knew his county did not offer comprehensive coverage to undocumented immigrants, and they understood that his legal status rendered supportive services such as housing and disability resources impossible. During a clinic visit, the CCM nurse laid out Hector’s situation from her perspective. She explained that many blind people were able to live independently through availing themselves of a range of support services. Unfortunately, these services did not apply to people without papers. After considering his precarious situation from all angles, she asked cautiously (in Spanish), “Can you return to live in

Guatemala?” She knew that for Hector to return home because he could not meet his medical needs was the worst-case scenario. Hector steeled himself, hands on his knees, as he answered, “I’ve almost reached that point.” The problem was, according to him, that there was no way he could get the care he needed in Guatemala. Now he had to decide whether to die in the U.S. without access to care or die there with inadequate care.

The nurse explained that she would get in touch with a doctor in another county bordering Hector’s to explore options there. Meanwhile she would not prevent his continuing to seek care at her clinic, but she stressed that they needed a more realistic solution. “There are few things we can do from here. This plan to live [there] and get your medical care [here] makes no sense,” she said firmly. “I feel frustrated, too,” she added gently. “Your situation is truly breaking my heart.” Later, as the nurse returned to her office, she reflected on the range of difficult cases she managed as a CCM nurse. “I like hard,” she remarked seriously, “but this is impossible.”

Hector’s case underscores how complicated matters of geography result in differential enactments of citizenship and health. Had he been born in the U.S. rather than Guatemala, citizenship status would not have complicated his healthcare crises. (His ethnicity, education, and income may have, but not his legal status.) As his nurse observed, the U.S. healthcare safety net includes certain provisions to ensure basic support services for citizens with disabilities. Furthermore, had Hector settled in our study’s counties rather than a neighboring one, it would have ensured a level of social citizenship corresponding to a sanctuary ordinance coupled with a county-based universal health coverage program. Locally, a matter of some sixty miles separated Hector from a robust and inclusive healthcare network. Federally, however, stratified notions of immigrant deservingness resulted in exclusionary health and social service policies, creating a gulf that was impossible to traverse.

“It dismantles you, little by little.”

Like many of the other immigrant patients we observed, Cristiano struggled in the U.S. He spoke only Spanish, was not literate in any language, and his health was declining. He recounted numerous experiences of class and racial discrimination, including interactions with the criminal justice system. Cristiano also had been separated from much of his family for decades because he could not return “home.” Yet his legal status set him apart from many of the other immigrant patients we met. In our first interview with Cristiano, he explained how he came to the U.S. from Cuba in 1980 during the brief diplomatic window known as the Marielito boatlift. Until 2017, Cuban nationals who emigrated to the U.S. were eligible for legal permanent residence after only one year in the country (U.S. DHS, 2017). This distinguished them from refugees and asylees from other countries, who required substantial documentation and frequent adjustments of status before potentially obtaining a green card. Thus, unlike other immigrant patients, U.S. law considered Cristiano a lawful political immigrant and granted him legal residence. It also meant that, under the 1996 welfare and immigration reform laws, he was one of the explicit “exceptions” eligible for many services that other immigrants could not access, such as subsidized housing, supplemental income, in-home care, and full Medicaid and Medicare benefits. This was

fortunate for Cristiano because he suffered from diabetes. Now in his seventies, he was dealing with many of its complications, including eye disease and failing kidneys.

When Cristiano's daughter, with whom he lived in public housing, died suddenly, his son invited Cristiano to live with him in a nearby county. Cristiano refused, however, in part because he could not bear to leave his community or his clinic. Had he done so, he would have lost both his closest friends and his dedicated local healthcare team. Although his legal status would have allowed him to access health and housing services in another county, he felt he could never leave the place where he had built a life and relationships over forty years, especially in the city's Latinx community. "No," he declared, "I'll die here." And his legal status made this choice possible. He was re-housed in a one-bedroom flat in the same public housing complex where he had been living, and he continued to receive the in-home care that allowed him to live relatively independently. He also continued participating in the CCM program, enabling him to manage his diabetes better than he could on his own and delaying his transition to dialysis.

To be sure, Cristiano's health caused him much trouble, including multiple near-death experiences. He told us dejectedly, "As years go by, diabetes starts taking things from you. A toe, a foot. It dismantles you, little by little. That's what diabetes does to people." But with the help of the county clinic, Cristiano had some capacity to manage this dismantling. For nearly forty years, he had access to adequate medical care as well as housing, income, and in-home support services. Unlike other patients we interviewed, he did not jump from diabetes diagnosis to dialysis in one fell swoop. As a legally present, legitimate immigrant, he was able to access primary care to treat his diabetes in ways that "unqualified" immigrants frequently could not. Instead of receiving a diabetes diagnosis after already suffering kidney failure (as Eladio had) or going blind (like Hector), Cristiano's disease progressed gradually. Although he and his CCM providers were disappointed that he ultimately needed dialysis, they were comforted by the fact that they had forestalled it as long as they did.

"I hope they don't take away my insurance. That's the only thing I hope for."

Miriam was one of the few immigrant patients we interviewed who had become a naturalized citizen. Now in her fifties, she had come from El Salvador many years before and had managed diabetes since she was a child. She remembered slipping into a coma two times while growing up, unable to assess her blood sugar and adjust her insulin accordingly. According to Miriam, improvement came about only when she was approved for an insulin pump in the U.S. When she was working and had private insurance, high premiums and co-pays prevented her from getting the medications and insulin pump that she needed. When she could no longer work, she applied for disability and Medicaid and qualified for the pump shortly thereafter.

In comments that echoed Watson's (2014) and Horton's (2016) findings, Miriam's gratitude for the pump was tempered by her reluctance to over-use Medicaid – apparently because of the stigma around public benefits use. She sometimes had trouble following all the instructions she received and recounted one instance when her physician shamed her for appearing to be ungrateful for a service he said she "wasn't even paying for." Miriam got a

new doctor after that, but she still expressed concern over the possibility of losing her Medicaid coverage because she was a Latina immigrant. She perceived that people often collapsed all Latinx individuals into an undifferentiated mass of delinquent Mexicans rather than considering their heterogeneous experiences and origins, and she worried what this might mean for her own health. In one of Miriam's interviews, which took place a few days before the 2016 presidential election, she said, "[Trump] doesn't like Mexicans ... The only thing that is missing is for him to remove [Medicaid] for those of us who are illegal—I mean, for those of us who are not born here."

Miriam's slip of the tongue, referring to herself as "illegal" when in fact she was a U.S. citizen, signaled her anxiety over the way Latinx individuals were being depicted in the media, and often treated by institutions, as self-evidently undocumented. She worried about how the media associated her community with violence and criminality, and she stressed the ways in which she was a good citizen who thus ostensibly deserved Medicaid – for example through her employment record and tax contributions. For Miriam, Medicaid had made an enormous difference in her quality of life, but she believed that growing anti-immigrant sentiment could have direct consequences for her health.

5. Conclusion

Our study initially set out to examine CCM programs in the safety net, and legal status emerged as a key structural determinant of participants' health. While the fact that we did not ask patients explicitly about their legal status limits the precision with which we can categorize each participant, it allowed us to build rapport and avoid the warranted suspicion that such direct questions may raise among immigrant patients. Furthermore, years of shadowing CCM providers at our research sites enabled us to observe how legal status affected immigrant patients in practice and over time, and these observations were often supplemented by the reflections of immigrant patients during semi-structured interviews.

Our data thus empirically illustrate that legal status intersects with other structural vulnerabilities, and when layered onto multi-leveled policies, persists in shaping the health of immigrants in the U.S. – even in immigrant-inclusive locales. The cases presented here correspond to varying strata of citizenship status and their subsequently stratified health and social service support possibilities. Undocumented patients Eladio, Manuel, and Hector all succumbed rapidly to chronic disease complications and required resources that remain beyond the reach of "unqualified" immigrants, such as housing, income, and disability support. Both Eladio and Hector had come to the U.S. to work, and both lives were derailed when that work became impossible due to illness. Manuel, on the other hand, considered himself a political refugee but did not benefit from the type of legitimacy that the U.S. conferred upon Cristiano and his compatriots. Like Cristiano, Miriam's legal presence in the country meant she faced one less obstacle to health compared to Eladio, Manuel, and Hector. Yet Cristiano and Miriam both expressed concern over the discrimination they had faced in the U.S., and particularly in healthcare encounters, in ways that suggest – as Asad and Clair (2017) theorize – the *de facto* discrediting of their *de jure* legal status. Nevertheless, though chronic illness caused all of these patients great distress, those with legal status possessed personal and institutional safety nets that extended beyond "medical" interventions to

encompass services such as housing, income, and disability support. The specific position occupied by these patients on the continuum of legal status stratification thus shaped their health potential in the face of chronic illnesses.

As chronically ill patients in the safety net, all CCM patients – whether born in the U.S. or abroad – share ongoing struggles not only with illness, but also structural barriers to health such as poverty and a severe shortage of affordable housing. The immigrants we observed confronted an additional structural challenge, however, which also complicated CCM’s work. Despite progressive local policies, a relatively robust medical safety net system, and care teams’ willingness to go the extra mile to assist non-citizens, CCM programs struggled to serve many of their immigrant patients. The absence of legal status also meant the absence of comprehensive socio-medical support options and limited social networks.

Our study answers the call to take citizenship status seriously as a structural determinant of health and source of inequality, and it contributes empirical evidence to support the claim that stratified legal status matters for health outcomes. We find that national immigration and health policies are at odds with patients’ needs and care teams’ efforts to address them. The federalism of U.S. immigration policy, and the uneven ways these are layered upon one another and enmeshed at the state, county, and municipal levels, results in geographic stratification in treatment options across neighboring counties. This highlights the differential emplacement of social citizenship across space and underscores the limited ability of locally progressive policies to overcome multilayered, entangled structural vulnerabilities, such as stratified legal status, socioeconomic and political disadvantage, and the unequal distribution of housing and healthcare resources.

This latter point is particularly troubling as healthcare and immigration policies become more exclusionary under the current federal administration. While many of the patients we observed benefited from locally funded health and sanctuary policies, these protections were limited by federal restrictions, and their power evaporated at the county line. Now, as the ACA continues to be targeted with alteration by government leaders (Kirzinger et al., 2017), and as federal immigration enforcement agencies take action against sanctuary jurisdictions (Westervelt, 2017), the inclusionary practices of our study sites are under fire. The importance of immigration status will likely increase as a key determinant of health in the months and years ahead, with serious material consequences for chronically ill immigrants.

Our data underscore how legal status is stratified both horizontally across space and vertically along a continuum from undocumented to naturalized citizen status – with many “liminal” statuses between these two poles (Menjívar, 2006). Future scholarship, such as that underway by Joseph (2016), should explore how this liminal legality shapes immigrants’ health potential – both at the individual and group levels. Further, as Van Natta (2018) suggests, research is also needed to ascertain how contemporary policy uncertainty at the federal level interacts with local structures and practices to impact the health decisions of immigrants and those who provide their care in the safety net. Confusion over potential policy changes, such as the inclusion of Medicaid in the list of public benefits that count as a “public charge” against immigrants’ status adjustment, will have major consequences for low-income, chronically ill immigrants across the legal status spectrum (Perreira et al.,

2018). Future research, particularly through ethnographic observations, is needed to shed light on the individual-and group-level consequences of these macro-level disruptions.

Acknowledgements

We are grateful to our study participants for sharing their time and attention during observations and interviews. We also recognize the contributions of our co-investigators Elizabeth Davis, Kathleen Dracup, David Moskowitz, and Dean Schillinger. Research reported in this publication was supported by the National Institute of Nursing Research of the National Institutes of Health under award number R01NR015233–02.

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