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Navigating a Fragmented Health Care Landscape: DACA Recipients' Shifting Access to Health Care

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Abstract

Deferred Action for Childhood Arrivals (DACA) recipients face an uncertain fate as their future in the United States is being debated. Yet even before the program was introduced in June 2012 and became endangered in September 2017, they encountered challenges in navigating a fragmented health care landscape throughout the United States. This paper focuses on DACA recipients' experiences in accessing health care throughout their lives, both before and after receiving DACA. We conducted semi-structured interviews and questionnaires with 30 DACA recipients living in Maryland between April-December 2016. Participants represented 13 countries of origin and ranged in age between 18-28. Results demonstrate that DACA recipients have had punctuated coverage throughout their lives and continue to face constrained access despite temporary gains in status. Health care access is further stratified within their mixed-status families. Participants have also experienced shifts in their health care coverage due to moving between jurisdictions with variable eligibility and changing life circumstances related to family, school, and employment. This article underscores the importance of examining young adult immigrants' access to care over time as they weather changes in the broader policy context and in highly variable contexts of reception nationwide, shaped by state, but also county and city policies and programs. The challenges and gaps in coverage DACA recipients face also underscore the need for both health care and immigration reform.

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Keywords

Immigrant/immigration; Law and policy; State-level policy; Health and wellness; Health inequalities; DACA; Young adults; United States

Introduction

The uncertain fate of Deferred Action for Childhood Arrivals (DACA) recipients has garnered increasing public attention since President Trump assumed office in January 2017 and rescinded the program in September 2017. President Obama created DACA in June 2012 by Executive Order as a stop-gap measure to address the plight of some 2.1 million immigrant young adults in the absence of more comprehensive immigration reform, which has long stalled in Congress (Batalova et al. 2014). DACA provides work authorization and protection from deportation for qualifying young adults who immigrated to the United States as children but came of age undocumented in U.S. schools and communities; it is a temporary status (as opposed to a pathway to citizenship) that must be renewed every two years through an extensive and expensive application process (National Immigration Law Center 2018a).

Since the program began, nearly 800,000 undocumented young adults received DACA (Capps et al. 2017). DACA has concretely changed recipients' life trajectories, giving them economic opportunities such as increasing access to higher education, getting their first jobs in the formal economy, securing new jobs that align with their professional goals, and earning higher wages; it has also allowed them to obtain driver's licenses, open bank accounts, acquire credit cards, and purchase homes (Gonzales and Bautista Chávez 2014; Pérez 2014; Wong et al. 2016). These strides in the immigrant incorporation process had previously eluded them (Abrego and Gonzales 2010).

However, when President Trump rescinded the DACA program on September 5, 2017, it left DACA recipients' fate in further limbo. Multiple lawsuits challenging the rescission were filed in the subsequent months and are working their way through the federal courts; however, in November 2018, a federal appeals court ruled against phasing the program out, declaring the government could not immediately end it. Meanwhile, the administration asked the Supreme Court to take up the case before the courts are able to issue decisions, though it is unclear if that will happen. For now, current DACA recipients can renew their status, but no new applications are being processed (National Immigration Law Center 2018b). DACA recipients remain in a prolonged state of liminal legality (Menjívar 2006), characterized as a gray area between having status and being undocumented with the ever-present fear of potentially losing their status.

Though DACA is a federal-level executive order, states and localities have also been enacting policies since the early 2000s to address immigration in the absence of broader comprehensive reform at the federal level (Cebulko and Silver 2016; Varsanyi et al. 2010). States introduce around 1,300 immigration-bills each year, with an average of 200 becoming law (Philbin et al. 2017). The year 2017 was a record one, with 204 laws and 269 immigration-related resolutions enacted (American Immigration Council 2018). Great variability exists in the state-level policy context, leaving immigrants and their children to negotiate a “multilayered jurisdictional patchwork” (Varsayni et al. 2012). Golash-Boza and Valdez (2018) argue that the policy context must be conceptualized as “nested” contexts of reception, consisting of marked federal-, state-, and local-level differences that create different living and working conditions for immigrants.

State-level policies play an important role in legitimizing or delegitimizing the presence of DACA recipients specifically (Cebulko and Silver 2016). California is well known for having the most favorable policy climate nationwide, including the passage of AB 540, 130, and 131, which granted undocumented young adults in-state tuition eligibility, opened up private scholarships to them, and allowed them to apply for state financial aid, respectively (Golash-Boza and Valdez 2018). Beyond California, states like Massachusetts have adopted more inclusive policies, such as in-state tuition eligibility and driver’s licenses (Cebulko and Silver 2016: 1558). By contrast, states like North Carolina have enacted restrictive policies, such as promoting training for local law officials to enforce immigration law through the 287(g) program and introducing bills to ban undocumented students from community colleges and state colleges and universities (Cebulko and Silver 2016:1558). Through a social determinants of health framework, even these educational and social policies should be considered as being fundamentally health policies (Castañeda et al. 2015; Philbin et al. 2017), shaping the broader health and well-being of immigrants.

Health care is also a realm in which immigrant young adults encounter marked variability. In the realm of public insurance, at the federal level, undocumented and DACAmented immigrants are explicitly ineligible from federal public health insurance programs and even lawful permanent residents face a five-year eligibility ban per restrictions laid out in the 1996 welfare reform law (Castañeda and Melo 2014; Horton 2014). The Affordable Care Act of 2010, which was touted as a means of reducing disparities in health care by extending access to underserved populations, upheld the 1996 eligibility restrictions for immigrants, including specifically for DACA recipients. Given these restrictions, many immigrants gain access to health care services at community health clinics (including at Federally Qualified Health Centers) and public and teaching hospitals; under the ACA, however, these facilities have faced further challenges in funding and due to the rationalization of care, often borne by safety-net providers and brokers who bridge access to care for immigrant patients (Getrich et al. 2018; López-Sanders 2017). It is possible that DACA recipients have gained increased access to employer-based health coverage since their work authorization provides expanded employment options in the formal economy; however, it is still unknown the extent to which DACA recipients’ access to health care has improved (Kaiser Family Foundation 2018).

State-level policies have expanded immigrants’ access to health care in some states, while constraining them in others (Philbin et al. 2017). Though the majority of states have followed the exclusionary lead of the federal government, a few have diverged in their approach. California, Illinois, Massachusetts, New York, Oregon, and Washington have all expanded their Medicaid programs to all income-eligible children, regardless of immigration status (National Council of State Legislatures 2017). Some county- and city-level jurisdictions have experimented with alternative models of care, offering coverage to undocumented residents of Alameda County, California (Hirota et al. 2006) and San Francisco (Marrow 2012). Washington, D.C. also created its locally-funded D.C. Health Care Alliance program to be inclusive of District residents ineligible for Medicaid, including undocumented immigrants.

This article considers the implications of these “nested contexts of reception” (Golash-Boza and Valdez 2018) by examining DACA recipients and their family members’ coverage in Maryland. We consider not only how fragmentation by state factors into health care access for DACA recipients, but also how cities and counties play a crucial role in constructing policies that assess immigrants’ eligibility differently. In addition to variable access, however, DACA recipients encounter other types of fragmentation: stratification in access within their mixed-status families, changes in coverage when they move between jurisdictions, and gaps in coverage due to changing life circumstances. We highlight these different forms of fragmentation amidst the backdrop of this “multilayered jurisdictional patchwork” (Varsayni et al. 2012).

Background

Much of the focus of the burgeoning literature on DACA has been on education and workforce participation, with a secondary focus on other facets of daily life, like driving and banking. The health and well-being of DACA recipients is understudied (Gómez and Castañeda 2018; Patler and Pirtle 2017), yet it influences recipients’ abilities to gain incorporation in these other realms since health is interrelated with other aspects of daily life including school, work, and family relationships. There is increasing attention to immigration policies like DACA as social determinants of health (Castañeda et al. 2015; Philbin et al. 2017) and recognition that immigrant legal status serves as a central axis of stratification in U.S. society (Menjívar 2006; Patler and Pirtle 2017;).

Existing in a state of prolonged limbo has implications for undocumented young adults’ mental health (Castañeda and Melo 2014). Undocumented youth have been found to exhibit high levels of depression and anxiety due to chronic stress and fear of deportation (Raymond-Flesh et al. 2014; Siemons et al. 2017; Stacciarini et al 2015). Transitioning from undocumented status to lawful presence has positive emotional consequences (Patler and Pirtle 2017; Venkataramani et al. 2017), not only fostering a positive sense of self for recipients, but also increasing their social support and social integration (Siemons et al. 2017). Yet even with the mental health benefits of DACA, recipients continue to face gaps in mental health services and a lack of culturally competent and bilingual providers (Raymond-Flesh et al. 2014). Beyond that, many DACA recipients’ mental health gains are undermined by their concern over the vulnerabilities of other family members who remain undocumented (Patler and Pirtle 2017; Sudhinaraset et al. 2017).

Both undocumented and DACAmented young adults face barriers in accessing health care more broadly (Raymond-Flesh et al. 2014). Starting in the 1990s, there was a dramatic shift towards an overtly restrictive immigrant healthcare delivery context (Castañeda 2010; Marrow 2012; Willen et al. 2011). The precedent for federally funded public health-insurance programs was set with the passage of the 1996 welfare reform law, the Personal

Responsibility Work Opportunity Reconciliation Act (PRWORA). PRWORA restricted public benefit access (Medicaid, Medicare, Child Health Insurance Program, income support, and food stamps) exclusively to immigrants residing in the United States under qualified status for five years or more (United States Department of Health and Human Services 2012). PRWORA represented the first time that citizenship was explicitly used as a factor in determining eligibility (National Council of State Legislatures 2017b).

Undocumented immigrants are ineligible for Medicaid per the 1996 welfare reform restrictions; even lawful permanent residents face a five-year eligibility ban (Castañeda and Melo 2014; Horton 2014). The ACA of 2010 extended the 1996 welfare reform restrictions, explicitly excluding both undocumented and DACAmented immigrants. Possessing DACA has likely contributed to increased access to employer-based health care for many DACA recipients, although data is just emerging and many still work in jobs without benefits (Kaiser Family Foundation 2018). If they are not able to access employment-based insurance, they are likely underinsured or uninsured, relying on safety-net institutions for health care like their undocumented counterparts (Horton 2014; López-Sanders 2017; Raymond-Flesch et al. 2014). Beyond insurance, additional barriers to care include cost, limited intergenerational knowledge about the health care system, and mistrust of providers due to fear of discrimination and/or deportation (Raymond-Flesch et al. 2014).

DACA recipients live in mixed-status families, whose members possess different immigration statuses. Scholars have increasingly noted that status vulnerabilities extend beyond undocumented immigrant adults, implicating even citizen children in mixed-status families (Dreby 2015a,b; Zayas 2015). Fear of deportation, in particular, penetrates family life, unsettling children's sense of stability while causing anxiety and *nervios* (Dreby 2015a,b; Zayas 2015) and even shaping children's health care usage (Zayas 2015:65). Immigration enforcement policies—which are reaching new heights under Trump—also produce harmful effects not only for undocumented immigrants and their families, but immigrants of all statuses and citizens of color who are profiled (Getrich 2012; García et al. 2017; LeBrón et al. 2018; Novak et al. 2017; Philbin et al. 2017; Sabo et al. 2014), including through state-level policies like Arizona's SB1070 (Hardy et al. 2012).

Even before the rescission of DACA, DACA recipients' ongoing health and mental health conditions, their constrained access to health care, and the vulnerability of their family units rendered them medically underserved. However, given the uncertainty surrounding the program and amplification of federal enforcement actions affecting members of their social networks, their embodied health conditions are intensifying. Yet we know little about how DACA has changed their access to care and how recipients are navigating the realm of health care during this time of immigration-related insecurity, let alone throughout their lives.

Methods

This article draws from the DACA Health and Well-being Study, for which we obtained ethical approval from the University of Maryland Institutional Review Board. In 2016, Maryland had the 12th largest concentration of DACA-eligible populations nationwide

(Hipsman et al. 2016:7). As of September 2017, 9,957 applications in Maryland were approved out of 34,000 individuals estimated to be eligible (U.S. Citizenship and Immigration Services 2017; Migration Policy Institute 2017). Maryland has been characterized as a DACA-"friendly" state (Henderson 2014), due to its practice of allowing undocumented immigrants to access driver's licenses and its 2012 state DREAM Act ensuring tuition equity for undocumented students. However, unlike nearby Washington, D.C., it does not allow undocumented or DACAmented immigrants access to publicly-funded health care. Maryland's DACA recipients are more diverse in national origins than many other states; the largest countries of origins are El Salvador (21%), Mexico (15%), Guatemala (12%), and Korea (6%), with the remaining 46% from other countries (Migration Policy Institute 2017). Nationally, Mexicans are the largest proportion of DACA recipients; however, Maryland's demographics reflect the relatively smaller Mexican population, the large presence of immigrants from Central American and Asian countries of origin, and the immense diversity of the Washington, D.C. metropolitan area.

Recruitment

DACA recipients are not a cohesive community, but rather are a group defined by their common bases of experience: immigrating as young children, spending at least part of their childhoods as undocumented, possessing the same form of temporary status, and being young adults (age 31 years old or younger on June 15, 2012). Conducting research with a group characterized by its vulnerable status, youth, and loose organization requires special sampling and recruitment considerations (Singer 2013:259). We consciously recruited in community settings to reach a wide range of participants; despite these efforts, the majority of our sample (90%) ultimately was enrolled in a community college or university, though some on an extremely part-time basis secondary to work. Our initial strategies consisted of tapping into research team members' personal networks, distributing a recruitment flyer through youth-focused community-based organizations, and posting a recruitment flyer to a local social media group organized around DREAMer activism; these strategies yielded an initial 13 participants (seven, three, and three, respectively). We then solicited referrals from these participants, utilizing a snowball sample. A snowball sample was particularly appropriate for this "hidden population" (Singer 2013) as many participants deliberately withhold information about their status from their peers and others in their lives; thus, recruiting participants via trusted contacts was absolutely critical. An additional 17 participants were referred to us (six from social networks, 10 from those recruited from the community-based organization, and one from the local social media group). Our sample clustered in two Maryland counties adjacent to Washington, D.C.—Montgomery and Prince George's—that also have the largest concentration of DACA recipients in the state (Migration Policy Institute 2017).

Data Collection

We conducted data collection between April and December 2016; thus, our findings largely provide a snapshot of DACA recipients' lives before Trump took office and DACA became endangered. However, data were collected during an election season in which immigration was strongly featured in public discourse. Participants reflected extensively on the potential impact of the election, which weighed heavily on their minds, particularly as it drew closer;

they often mentioned the election before we even had the chance to ask about it. Research activities took place at the participants' choice of location, including private rooms at the University, workplaces, public parks, and coffee shops. Participants filled out a 4-page questionnaire and then participated in a semi-structured interview lasting between 45-90 minutes.

The questionnaire collected demographic data, such as age, gender, ethnicity, country of origin, household composition, income, educational, and language use. It also included measures adapted from the Health Information National Trends survey (HINTS) that gauged access to health care and health-seeking practices, such as health insurance/health coverage, type of coverage, frequency of visits to a health professional, self-report rating of health status, diagnosed conditions, and social networks (National Cancer Institute 2018) as well as the validated Patient Health Questionnaire (PHQ-4) to screen for psychological distress (Kronke et al. 2009). The semi-structured interview assessed participants' lives pre- and post-DACA, exploring participants' immigration story, experiences finding out about and applying for DACA, the impacts of DACA, DACA's influence on their health, their changing health status and state of mind, and overall well-being and belonging. Sample questions included: *Before you got DACA, what did you do when you got sick? Have you tried to get health insurance since you got DACA? Has DACA changed how you access health care at all?*

Data Analysis

We created a codebook and entered questionnaires into the Statistical Package for the Social Science (SPSS) program. Given the small sample size, we use the questionnaire data largely for descriptive purposes. The PHQ-4 also provided a concrete assessment of participants' mental health status. All interviews were recorded (with permission) and transcribed verbatim for subsequent analysis, which followed principles of grounded theory (Charmaz 2011). We first analyzed interview data by open coding to discover themes and topics by selecting an initial set of transcripts to review individually (Emerson et al. 2011). We then met as a team to review the set of transcripts line by line, identifying and refining codes, and establishing a preliminary coding tree. Next, we chose another two transcripts to test and refine the preliminary coding tree, continuing that process until we constituted the full set of codes and reached consensus about their application. The three team members then coded a set of three transcripts to ensure inter-rater reliability. Once the coding tree was finalized, we coded transcripts in NVivo 10 and then generated coding reports to review as a team.

Parent codes that largely mapped onto interview guide domains included: immigration story, family/social network, school, work/employment, DACA experiences, health (physical and mental), health insurance, health-seeking behavior, belonging/identity, political climate and policy, surveillance and document security; the final code was an emergent one especially tied to the shifting sociopolitical climate. This article stems from the parent codes health, health insurance, health-seeking behavior, and political climate and policy. Several children codes such as stratification within family and local variation in coverage and health programs (health insurance); healthcare experiences, decision-making, and connecting to health resources (health-seeking behavior), and elections and state/local variability (political climate and policy) emerged as important to understanding access and allowed us to interpret relationships between codes.

We examined our participants' access to health care specifically via questionnaire measures that assessed participants' current health insurance status, type of health insurance (employer-based, self-pay, college/university coverage, and government program, such as Medicaid), and usual source of non-emergency health care. In the interviews, we also gathered a more comprehensive health history, looking at their access (when they were minor children, before they received DACA, and after they received DACA) as well as broader health care seeking patterns to better understand their engagement with the health care system over time.

Follow-Up Research

Subsequent to the initial 2016 data collection phase, we presented preliminary results in several fora, including a community event in March 2017 for which we invited research participants and their supporters to provide feedback. The event served as a participant check to support the trustworthiness of the study (Morrow 2005), validating these findings. Between November 2017 and July 2018, we completed a second phase of research involving, among other activities, follow-up surveys and interviews with 25 out of 30 of our original research participants tracking the effects of the DACA uncertainty. This article focuses principally on the initial 2016 phase, though we include relevant details from the follow-up phase to highlight continued changes to participants' access to health care (i.e., loss of insurance).

Results

Demographics

Thirty DACA recipients participated between April and December 2016 (see Table 1 for Participant Demographics). Participants had had DACA for up to four years maximum if they applied for the program immediately when it was announced in 2012. Participants hailed from 13 different countries of origin (grouped into regions to protect anonymity). Half (15) were born in Central American countries, while 7 (23%) were born in South America, 3 (10%) were born in North America, 3 (10%) were born in Asia, and 2 (7%) in Africa. Our sample reflected Maryland's predominance of Central Americans, large presence of Asians, and notable diversity of national origins. Participants arrived to the United States between the ages of 2 and 15, with a median age of 8 upon arrival. We interviewed more females (21; 70%) than males (9; 30%) and participants were a median age of 21, ranging between 18 and 28. Participants were evenly split between two counties of residence: Prince George's and Montgomery. As previously noted, the majority of participants (27; 90%) were enrolled in a community college or university when interviewed.

DACA Recipients' Access to Health Care and Engagement with the Health Care System

We identified four categories that captured DACA recipients' access to health care over time: punctuated coverage throughout the life course, variable access within families, changes in coverage due to moving, and shifts in coverage due to changing life circumstances.

Punctuated Coverage throughout the Life Course—We found that participants' access to care was punctuated throughout their lives. Most described their access to care as being extremely limited when they were children and/or before they received DACA. As one 21-year old Honduran, Lucia, succinctly stated it, "When I was a kid before I had DACA, I never really went to the doctor." Instead, participants reported only going to clinics for mandatory school physicals or immunizations, delaying care because of the cost (or fear of the bill), relying on home remedies, and seeking care at community health clinics only when absolutely necessary—practices they shared in common with other underserved family members.

Those who did have access to care as children were surprising knowledgeable about the specific names or details of the programs (e.g., Medicaid and Care for Kids). Most (but not all) of the 15 participants who lived in Montgomery County were able to access the county-funded Care for Kids program that provides county residents who are minors with insurance regardless of immigration status, having found out about the program through their local schools or social networks. For those who qualified, the program was invaluable in helping them meet their health care needs. However, no such program was available to the other half of our participants who lived in next-door Prince George's County when they were children. Another limitation of the program is that it is only for minors; thus, all of our participants eventually aged out of the program. As 20-year-old Annisa, who is originally from Malaysia, noted, "We were able to use Care for Kids while there was time. But past 18, it was like, 'Where do I go now?'" Annisa has not had a reliable source of health care since then, as neither her parents' or her jobs have had benefits.

When we collected data in 2016, participants' health insurance status was as follows: nine (30%) were underinsured (possessing a minimal coverage plan, a limited student plan, or a high-premium/high-deductible plan); seven (23%) were altogether uninsured; six (20%) were insured through their jobs (which having the work authorization through DACA had helped them secure); six (20%) were insured through their parents' jobs; and two (7%) were temporarily covered through a charity care program.

We regard the underinsured as having access to an inadequate level of coverage based on benefits available and out-of-pocket costs relative to income (Blewett et al. 2006). The largest subcategory of underinsured were those who purchased minimal coverage or university plans. The university systems that many participants attended required that they prove health insurance status to enroll. While many universities offer their own Student Health Insurance Plans (SHIPs), most of our participants simply found the cheapest possible plan; as Annisa explained, "I went online and found the one that cost the least. We just got it so that we don't have to be billed $1,500 upfront for the university insurance. But it's very, very limited—I don't think I can even use it for regular doctor checkups."

In addition to those who were underinsured, seven individuals (23%) lacked health insurance altogether; thus, slightly more than half of our sample (53%) was underinsured or uninsured.

Elisa, a 20-year old Honduran, had worked at a drug store while she was undocumented in high school, but secured a better-paying job in a doctor's office post-DACA. At her front-desk job, she sets up appointments, checks patients' insurance status, and determines co-pays. Yet insurance has remained elusive for her; as she shared, "They don't really pay me much at my job and I don't get insurance. I tried to search for insurance online, but I don't really have that financial stability to be able to afford it." Elisa was hopeful that she would be able to parlay her experience to a better position; as she said, "I'm hoping to switch over to a hospital in D.C. next month. If I get that job, hopefully I'll be able to get insurance. Everyone needs insurance just in case." Never having had insurance as a child, Elisa has become more acutely aware of the need for it working within the health care system.

Another 40% of participants had employer-based insurance, either through their own (six participants) or their parents' work (six participants). As we began our research, we hypothesized that DACA recipients would continue to face challenges in accessing insurance despite their gains in employment; indeed, we found that only six individuals (20%) had been able to get health insurance through the jobs in the formal economy secured with their newly acquired work authorization. Five of these individuals were employed by immigrant-serving non-profit organizations that were particularly dedicated to providing benefits to employees. Angélica, a, 25-year old Honduran who worked at one of these non-profits, recalled, "I was so thrilled when I found out I would get it because it was the first time in my life I had insurance. I was like, 'What, I can actually go to the doctor now?!'"

The six who had insurance through their parents' work had the best continuity of care; most of them were children of Temporary Protected Status (TPS) holders who had lived and worked in the United States for decades and accessed benefits through their work-authorized long-term jobs. Importantly, though, these individuals will likely lose their insurance if their parents' TPS expires and they can no longer work legally. Our participants are also aging out of their parents' plans at 26, as we found with Lucy (originally from El Salvador) when we did our follow-up interview with her in March 2018. It is important to note that even some who had insurance through their or their parents' employers may have had only bare-bones plans that would better be characterized as underinsurance; however, our 12 participants who had insurance described their employer-based insurance plans as adequately fulfilling their needs.

Our final two participants (7%) had accessed a health maintenance organizations' charity program, thanks to the diligence of their mother in gathering information via their social network and successfully navigating their way to it. Although this program served the two sisters well for two years, by the time of our follow-up interviews with them in April 2018, neither one had insurance any more, underscoring the short-lived access that charity programs often provide.

Variable Access within Families—In addition to gauging participants' access over time, we also contextualized it within their larger family units, also inquiring about their parents' and siblings' access to care. Our findings revealed great variability in coverage within families dependent on status. Most of the parents of our research participants were undocumented, though several fathers from Central American countries had TPS, and had been able to secure health insurance for themselves and their minor children (though not their undocumented spouses). The undocumented parents largely lacked coverage, which greatly concerned their young adult children. Twenty-eight year old Argentinean Rebeca lamented, “I try to help [my mom] if she has something hurting. But I feel like sometimes she doesn’t tell us when she’s feeling bad because she doesn’t want us to worry and take her to the hospital and have to pay the bill after.” Many participants talked about their family’s collective decision-making around avoiding medical bills they could not afford. In the absence of care in the United States, Rebeca’s family often calls her older sister, who still lives in Argentina and works as a nurse, to triage their health care needs. As Rebeca’s sister Yvette (who we also interviewed) noted, “Every time we were sick, my sister would tell us what we had, figure out what medications we could take, and then we’d look online for something that was similar here in the U.S. or she’d send medications to us.”

But the difference in coverage is not only apparent across generations. Though Rebecca and Yvette had both been in their mid-20s when they received DACA, Yvette was able to move through her schooling faster, land an internship in her field of computer science, and secure a job at that same workplace upon graduation. With this professional job came health insurance, which Yvette had had for more than a year when we interviewed her. When we asked her about it, Yvette noted, “It was such a relief when I got my insurance, because now I know that if I’m not feeling good, I can go to the doctor and check it out. Since I got my insurance, I think I’ve been to the doctor like four or five times [laughs]!” In addition, Yvette described the different quality of care she receives with her private insurance, saying, “It’s such a big difference when I go with my mom to see her doctor. When you have insurance, they treat you differently. When you go and have to pay, they don’t really do it the way that it should be.” By contrast, Rebeca spent 10 years (6 pre-DACA and 4 post-DACA) working through her Bachelor’s in psychology as she spent time getting certifications and working in positions that largely did not offer insurance, but meshed well with her student schedule.

The biggest disparity in access to and quality of care we observed, though, was between DACA recipients and their younger U.S.-citizen siblings. Many of our participants had younger siblings who were born in the United States, and, as such, had access to benefits that they did not. Annisa described how this difference played out in her mixed-status family, sharing, “Me and my brother both suffered from an ear infection around the same time. I did first and for a whole week, I didn’t go to school because it was really bad. My mom gave me medicine and painkillers. Then my brother got it and the first thing she did was take him to the hospital. He got medication and he was fine [quicker] than I was.” Even as a child, it was clear to Annisa how different their access to care was based on their status.

Beyond access, twenty-year old Mexican José noted that his three younger U.S.-born siblings benefitted from much better continuity of care, observing, “[My brothers] go to the same office where they’ve been going since they were babies. For them, the records are all in one place. For me, it’s different. Whenever I have to get vaccinations, it’s like a hunt when I’m trying to find out who has what information because my records switch from doctor to doctor.” Despite these notable differences, though José does not hold any resentment towards his brothers for the benefits they have. In fact, he reflected, “I wished I could have had that opportunity too, like they do. But then I just pushed it to the back of my mind. It became like, 'it is what it is.' I've just always seen it as everyone having their strengths and advantages. I just have a unique set of disadvantages."

Changes in Coverage due to Moving—Another unanticipated finding was how much access to care for our participants was shaped by varying local eligibility for programs. As we reviewed their access to care over time, it became clear that our participants had experienced disruptions in care as their families moved between jurisdictions, which many families did during their early years in the United States. For instance, José had insurance when he was younger, but then lost it when his family moved when he was 12 when his dad became unemployed and they relocated to Maryland to join family friends. As he recounted, "I had Medicaid for a while when I lived in California. I can remember going to the doctor very frequently for different reasons, like almost every month for something or another. But that stopped once I moved to Maryland. I had Medicaid at one point, and then I just didn't the next." Once José moved, he and his parents started seeking care at a local safety-net clinic "that serves people specifically in my situation. Only when I'm on the verge of dying or when I just can't stop the pain anymore, I'll go to the doctor." Thus, his engagement with the health care system declined considerably after he moved to Maryland.

Another 22-year old Mexican male, Brandon, also experienced a loss in coverage when his family moved, though this time within the D.C. metropolitan area. When his family first arrived, they moved to Washington, D.C., where a close friend of the family had settled. As he noted, "We were advised by the family we were staying with when we first got here to go ahead and get it. D.C. has more health benefits...even if you're undocumented. So, we had it for a good six years." When Brandon was 17, though, his family moved literally a few blocks away, but on the Maryland side. Once in Maryland, he noted, "there's no such thing as health care for undocumented immigrants. I haven't had health insurance since I moved to Maryland when I was 17." He stated that his family knew that they would lose their insurance in the process of moving, but that other more pressing reasons motivated their move.

At an even more local level, some participants experienced changes to their coverage when they moved between *counties*. The aforementioned Care for Kids program was extremely beneficial for Montgomery County residents; however, if families moved to a different county, those benefits ceased. This happened to several of our participants, including 18-year-old Honduran Denisse, who recalled, "When we lived in Montgomery County, there was a program that helped kids who were uninsured be able to go to the clinic. The program went with you anywhere you moved in the county—they'd connect you to where you'd moved." However, during her freshman year, her family moved to nearby Prince George's county; as she recalled, "When we moved back to PG County at the beginning of high school, that's when we lost it. And that's how it's been for us since—we've been without health care." Denisse noted, "Not [every county] has coverage, which sucks because some people need it more than others, but just because of where they live, they're not able to get it." Though the distance her family moved was not far, their change in county of residence had clear implications for their access to health care.

Shifts in Coverage due to Changing Life Circumstances—Participants also revealed other reasons for their shifting access, many related to their changing life circumstances, which were more fluid than we anticipated and shaped by evolving family obligations, work demands, and school schedules revealed in the interviews. Affordability emerged as a challenge for 21-year Honduran Nayeli. When she won a scholarship that paid for half of her school expenses, Nayeli took the initiative to purchase an insurance plan, stating, “I had a big bill last year, and started thinking, ‘Maybe I need to get health insurance so I can go to the doctor.’ I applied for my own health insurance and am paying for it by myself. I went online and picked my coverage plan. It’s not great, but I am insured.” During the follow-up interview we conducted with Nayeli in February 2018, though, we discovered that she subsequently had to let her insurance lapse as the premium kept rising and the family decided that her younger brother was in greater need of health care, thus diverting their collective resources to him.

Multiple participants described losing their insurance because they needed to cut back on full-time employment to be able to prioritize school. Rebeca revealed, “I had health insurance for a year because I was working full-time. It was wonderful—I was like, ‘Let’s do this exam and that exam and everything that needs to be done!‘” But then “I had to switch to part-time to take more credit hours. Now I’m down to per hour, so they don’t give me insurance any more,” Rebeca lamented. The most painful irony of Rebeca’s situation was that she worked as a Nursing Assistant, unable to access health care despite working in a clinical setting. When we interviewed Rebeca in 2016, she had been pursuing her degree for nearly a decade, and was eager to finally graduate. She needed to work the per-hour schedule to accommodate her academic schedule, even though it meant she would lose health insurance in the process. Rebeca made her peace with her decision, since she only had one semester of school left at that point, reasoning, “I had the insurance recently, so I’m pretty good for right now. Without it, I’d still be wondering and don’t think I would have had a check-up even now. Otherwise, I’d just have no clue what my health is.” Beyond that, she noted, “I’m hopeful that when I finish with school and am able to get a full-time job, that the insurance will come along with that.” Rebeca has continued on to graduate school in social work since then, and still lacks health insurance despite working three part-time jobs.

Rebecca was not the only one who worked in the health care field; in fact, six participants worked in health care and social service settings. Brandon started volunteering as a health advocate at a local hospital in high school before he could work legally. After graduation and before he received DACA, he continued volunteering at a community health clinic working with LGBTQ immigrants of color. During those years of volunteer work, Brandon came to understand the broader health care access landscape for immigrants, particularly in Washington, D.C. Of this time, he reflected, “When you’re working inside public health, you get to see many of its advantages but you also get to see many of its disadvantages and flaws...I don’t have health insurance, but at least I know [what that looks like] from the inside.” Eventually, his years of volunteering paved the way to being hired to work on a grant-funded project. Though he was uninsured when we interviewed him in 2016, he was able to gain coverage for the year in which he worked on the project. However, by our follow-up interview in February 2018, the project had ended and he was once again without insurance as he started a new part-time job to increase his course load for school.

Discussion

Though DACA was an important step in the right direction, DACA recipients are in need of more comprehensive policies that address deeper social determinants of health, such as immigration status (Siemons et al. 2017; Sudhinaraset et al 2017). Our study paints a nuanced picture of the challenges that DACA recipients have faced in negotiating a fragmented health care system throughout their lives, without status as children and with a legally liminal status as adults. Even though our sample was quite diverse in national origins (representative of Maryland more generally), we identified common bases of experiences (related to access to health care, changes to coverage with moves, shifts in life circumstances, and variation within family units) among participants from different countries and regions of origin. This suggests that many of these health care experiences are more rooted in the master status of being a DACA recipient (Gonzales and Burciaga 2018) than particular ethnic or national-origin group characteristics.

During their childhoods, our participants encountered differences in health care access depending on their state, and even county, of residence within the “multilayered jurisdictional patchwork” (Varsanyi et al. 2012). These differences were experienced most acutely when their families moved between jurisdictions (between states, from DC to MD, and between counties) and they lost coverage in the process. Though children at the time, DACA recipients felt these shifts acutely, and observed the corresponding changes in their lives and health. As children, they also detected differences between them and their U.S. citizen siblings that surfaced even as they suffered from the same illness, reflecting on the implications of status on quality and continuity of health care. Even though some of our participants were able to close this gap through the Care for Kids Program, all of them eventually aged out of the program.

Our study also underscores the importance of examining immigration-related policies across multiple levels (e.g., at the municipal, state, and federal level) (Philbin et al. 2017) within variable contexts of reception nationwide (Golash-Boza and Valdez 2018). Indeed, as immigrants move through different geographic spaces, they encounter variability that impacts their coverage and broader quality of life. In a large, multi-jurisdictional metropolitan area like Washington, D.C., a family’s move may be as simple as relocating only a few blocks away, but with significant implications for access to and continuity of care. Local moves may not even involve crossing state lines, yet different counties have variable access. Thus federal- and even state-level policies are not the only determinants of health care access for undocumented young adults.

We also found that it is important to understand how shifts in coverage play out over time and throughout individuals’ changing life circumstances. We found that DACA recipients’ health insurance status changed more throughout their lives than their undocumented or legally liminal immigrant parents and their U.S.-citizen siblings, who had less and greater access, respectively. Once they got DACA, and along with it, new jobs, our six participants who were able to get private health insurance through work relished in having insurance, in some cases, for the first time in their lives. They were able to establish regular doctors, visit those doctors frequently for a range of conditions, receive what they noted was higher quality care, and address long-neglected health conditions.

But for some participants, having insurance has been only a temporary stopover. Several participants had to drop back their hours for work to prioritize finishing school, losing their health insurance as they became part-time employees. This situation was particularly agonizing for those who also happened to work in the health care field, in the process becoming more acutely aware of the consequences of being uninsured. These decisions about how to manage their schedules and prioritize finances were difficult. Indeed, finances continued to influence health care access for participants who did not qualify for insurance through work. Nayeli, the participant who had so proudly purchased her own insurance policy online, quite simply could no longer afford it anymore in conjunction with all of her other expenses, including helping her younger brother pay for his insurance. Some participants like Elisa were never offered insurance at all in their full-time jobs and also did not make enough money to be able to purchase it, despite understanding its importance and wishing that their circumstances were different. Thus, half of our participants were uninsured, or underinsured with minimal coverage or student plans that did not fit their needs.

It is unclear what the future holds for DACA recipients in many aspects of their lives, including their health and health care access. Should the program be rescinded, those who are underinsured and uninsured will likely continue to occupy those categories and be further challenged by dwindling employment opportunities. Those who are insured through their job or their parents' job would be most affected by the rescission. If they lose their work authorization and are unable to retain their insurance through work, there are incredibly limited federal, state, or county programs to fall back on within the Maryland local context, let alone in most states and localities nationwide. They would likely have to rejoin their underserved parents and siblings in facing limited access to care in safety-net clinics, further widening the gap once again between them and their U.S.-citizen siblings. Even our most stably insured participants who have had their insurance through their parents are facing the possibility of losing it as their parents with TPS are also confronting the loss of their jobs and insurance in the near future. These losses in health care access would unquestionably undercut the modest gains in access that a limited number of our participants experienced.

Our study has several limitations. The majority of our sample was enrolled in college when data were collected; thus, we may not have represented the experiences of DACA recipients who are not also students as comprehensively. However, we also consciously sought to recruit participants from distinct countries of origin and across age categories to capture diverse DACA recipients' experiences. Our study focused on DACA recipients living in Maryland, whose experiences may be different from other DACA recipients nationwide. However, highlighting these geographical and jurisdictional differences—even within one metropolitan area—underscores the need to better capture different nested contexts of reception. This article thus serves as a call to better document the variable contexts of receptions that DACA recipients face in the realm of health care.

Conclusion

The uncertainty surrounding the DACA program is already having far-reaching public health consequences (Venkataramani and Tsai 2017). DACA recipients' current health care needs are quite acute given the uncertainty surrounding the program and the uptick in federal immigrant enforcement actions taking place nationwide, even in "immigrant friendly" local contexts of reception like Maryland. Future research should document continued shifts in DACA recipients' access to care, including mental health care in particular as they contend with prolonged uncertainty in their lives These threats to immigrants' health and well-being underscore the need to regard these immigration-related actions squarely within the realm of health policy.

The challenges DACA recipients face and gaps in coverage they have encountered throughout their lives underscore the need for both immigration and health care reform. With a more permanent status with a pathway to citizenship, at least some DACA recipients would be able to access health care through their more stable employment. For those for whom health insurance remained elusive, they would have some eligibility for a wider range of federal programs after the 5-year eligibility ban. However, these remaining constraints also underscore the need for more systematic health coverage for a broader range of individuals who live and work in the United States, immigrants of all statuses. These reforms need to more comprehensively address the circumstances of the 2.1 million undocumented and DACAmented immigrant young adults in U.S. society, but their also their family members since these policy decisions have broader ripple effects throughout immigrant families and communities nationwide.

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Table 1.

Participant Demographics, 2016

Birthplace (by region)	
Central America	15(50%)
South America	7 (23%)
North America	3 (10%)
Asia	3 (10%)
Africa	2(7)
Gender	
Female	21(70%)
Male	9 (30%
Age	
Range	18-28
Median	21
Age of arrival in U.S.	
Range	1-15
Median	8
School status	
Currently enrolled	27(90%)
Graduated high school	1(3%)
Graduated with Associate’s degree	1(3%)
Graduated with Bachelor’s degree	1(3%)
MD county of residence	
Montgomery	15(50%)
Prince George’s	15(50%)

[*] Participants’ birthplaces are grouped by region to protect the anonymity of participants who were the only individuals from their country of origin.