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“There Is No Help Out There and If There Is, It’s Really Hard to Find”: A Qualitative Study of the Health Concerns and Health Care Access of Latino “DREAMers”



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ABSTRACT

Purpose: Young immigrants without documentation who qualify for the Deferred Action for Childhood Arrivals (DACA) program are eligible for temporary legal status but excluded from the Affordable Care Act's Medicaid expansion and Health Care Exchanges. Little is known about this population's health or access to care.

Methods: Sixty-one DACA-eligible Latinos aged 18–31 years were recruited from community and Internet settings to participate in nine focus groups in California. An advisory board of immigration and health advocates assisted in the project's design and validation of results.

Results: Participants reported avoiding the health care system whenever possible, first turning to family members and unlicensed community healers, then seeking safety net providers if necessary. Barriers to care included cost, limited intergenerational knowledge about the health care system, lack of a driver's license, and mistrust of providers due to fear of discrimination and deportation. Mental health care was the greatest unmet health need. They wanted more information about their health care options and access to primary care, dental, and vision benefits. Participants reported refraining from high-risk behaviors to avoid associated financial and legal burdens that might threaten their immigration status.

Conclusions: As the first study to describe DACA-eligible young adults' health needs, these data demonstrate their profound mental health challenges and numerous barriers to health care access. Many barriers were attributed to their undocumented status and persisted even when they gained

IMPLICATIONS AND CONTRIBUTION

Young adults who are eligible for the Deferred Action for Childhood Arrivals (DACA) program have significant mental health concerns and face profound barriers to health care access. These barriers can be alleviated by immigration and health care reforms, as well as assurance of regular care through a medical home.

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temporary legal status. This work provides a foundation for evidence-based policy changes to address the health needs of this and other undocumented populations.

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Young adulthood, a stage of development that refers to those ranging in age from 18 years old into their mid-20s, is a period of major life transitions [1–3]. During this stage, individuals form lifelong habits and make important decisions about relationships, education, and careers [2–4]. Although young adults are generally healthy, they engage in risky behaviors and often develop harmful habits that shape their adult health [2,3,5]. Furthermore, young adults in the United States have higher rates of mortality from unintentional injury, homicide, and suicide and have greater need for reproductive, mental, and behavioral health care compared with younger peers [2–4,6,7].

For undocumented immigrants, the challenges of young adulthood are particularly complicated. Many undocumented young adults arrive in the United States as children and grow up unaware of their immigration status [8]. However, once they become aware, they face fewer educational and work options than US citizens and documented immigrants and often live with fear of deportation for themselves and their families [9]. Undocumented young adults are ineligible for federal financial aid for college, and, in most states, cannot apply for a driver's license, open a bank account, or apply for a credit card [8,10]. In addition, only 60% of immigrants without documentation complete high school compared with 92% of US-born young adults; only a quarter of these immigrants will complete college compared with 61% of US-born adults [9]. Although data on undocumented young adults are not widely available, studies of the broader undocumented population have shown that these immigrants have relatively high rates of uninsured status and poor access to health care [11,12].

The DACA program, established by executive order in 2012, provides some undocumented young adults with temporary work authorization and reprieve from deportation for 2 years, with the possibility of renewal (see Table 1 for eligibility criteria). Approximately 1.8 million young adults in the United States are, or will soon become, eligible for DACA, including 540,000 Californians [13]. Immigrants from Latin America make up over 90% of this DACA-eligible population [13,14]. Immigrants who are eligible for DACA are frequently termed "DREAMers" as they overlap with the population of immigrants who might benefit from the proposed federal Development, Relief, and Education for Alien Minors Act [13].

Although DACA enables these young adults to seek legal employment, their access to health care remains limited.

Although the Affordable Care Act will make coverage available to an estimated 32 million US residents, the Obama Administration announced in August 2012 that DACA recipients, like other undocumented populations, will be ineligible for expanded federal Medicaid coverage and barred from purchasing insurance through the State Health Insurance Exchanges, even without federal subsidies [15,16].

Thus far, little is known about the DACA-eligible population's health status, needs, or access to care. This qualitative study is the first to shed light on the health care needs and experiences of the largest population of DACA-eligible young adults in the United States—Latinos [14]. Such information is essential for providers, policy makers, and other national stakeholders as debates related to immigration reform receive increased attention.

Methods

An interdisciplinary research team from the University of California conducted a qualitative study utilizing community-based participatory methods [17], engaging a 10-member advisory board of immigration advocates and health policy stakeholders in study design, implementation, and validation of results. All procedures were approved by the University of California San Francisco Institutional Review Board.

Recruitment of this elusive population was guided by the advisory board and conducted by researchers, DACA-eligible summer interns, and community-based organization staff at sites such as legal aid clinics, immigrant advocacy groups, schools, and churches, as well as via email, social media (Facebook), flyers, and snowball sampling. Facebook and snowball sampling were the most successful methods of recruitment (Table 2). Participants were eligible if they self-identified as Latino, were 18–31 years old, were eligible for DACA (although they were not required to have received DACA), and were able to participate in focus groups in English. This study concentrated on Latinos as they represent more than 90% of DACA applicants nationally [14,18].

Nine focus groups lasting 60–90 minutes were conducted in Los Angeles and the Bay Area in summer 2013. Although 119 eligible people were recruited, a total of 61 participants took part in the focus groups. Despite efforts to retain participants via email, phone, and texts, the level of attrition remained around 45%, likely related to competing demands for participants' time and fear of disclosing their documentation status to researchers [19]. The study's advisory board assisted in identifying trusted Latino and immigrant-focused community organizations for focus group locations. Written identifiers of participants were minimized, and verbal consent was obtained from each participant to limit actual and perceived deportation risk. A written survey of demographic and health information was administered with each group. Themes covered in the groups were informed by existing literature about Latino immigrant communities and included health problems, health care access, and barriers to

Table 1
Eligibility criteria for the Deferred Action for Childhood Arrivals program [14]

Must be under 31 years old as of June 15, 2012
Must have arrived in the United States before 16 years of age
Must have resided in the United States continuously since June 15, 2007
Must have no felony convictions, serious misdemeanors, and fewer than three misdemeanors
Must currently attend school, have a high school diploma or General Equivalency Diploma, or have been honorably discharged from the United States military

Table 2

Characteristics of focus group participants

Total participants	61
Age, years ± standard deviation	22.4 ± 3
Female, n (%)	36 (59)
Latino, N (%)	61 (100)
Country of origin, n (%)	
Mexico	53 (87)
Other	8 (13)
Employment status, n (%)	
Full-time or part-time	46 (75)
Self-employed	3 (5)
Unemployed	15 (25)
Income <139% federal poverty level, n (%)	21 (43)
Student status, n (%)	
Full-time	31 (51)
Part-time	12 (20)
Not a student	17 (28)
High school graduate, n (%)	58 (95)
Military veteran, n (%)	0 (0)
Activist for immigration reform, n (%)	44 (72)
Insurance status, n (%)	
Uninsured	32 (52)
Privately insured	24 (39)
Publicly insured	5 (8)
Self-rated fair or poor health, n (%)	10 (16)
History of smoking, n (%)	15 (25)
At least one binge drinking episode in the past year, ^a n (%)	38 (62)
Depressed in the past month, n (%)	14 (23)
No usual source of care, n (%)	9 (15)
Recruitment method, ^b n (%)	
Social media	26 (43)
Community-based organization	24 (39)
Research flyers	6 (10)
Snowball sampling	22 (36)

^a A binge drinking episode was defined as less than five drinks for males or four drinks for females on one occasion.

^b Some subjects were recruited through more than one method.

health care, as well as how DACA might impact access to health care. The advisory board actively participated in the design of the study's demographic survey and moderator's guide. Participants received a \$20 gift card, a meal, and a resource list of immigrant-accessible health and social service organizations.

Three experienced qualitative researchers completed thematic analysis of the focus group transcripts. Identification and coding of themes were completed using modified grounded theory methodology [20]. Team members used an iterative process to identify example quotes and come to consensus on thematic definitions. Data were then further analyzed to identify subthemes and the relative importance of each theme. Preliminary results were shared at a convening of the advisory board and DACA-eligible young adults who validated the study's findings based on their experience with this population.

Results

The 61 focus group participants were 18–31 years old. Fifty-nine percent were females, and 87% were from Mexico (Table 2). Participants identified barriers to care and described the ways in which they attempted to seek care despite their limited insurance and health care options. They also identified a variety of health care needs, ranging from mental health problems related to their immigration history and undocumented status to difficulty accessing primary and specialty care due to their limited health care options. Finally, participants identified ways in which their immigration status was unexpectedly

protective, building resilience, and helping them to avoid high-risk behaviors.

Health care access and barriers

Sources of care. DACA-eligible young adults reported that for all but the most serious health care needs, they avoided care completely or sought care outside of mainstream medicine. Many participants sought health information online: "Even if it's something serious, I'll WebMD it. If it's something I can handle myself, I'll just take care of it myself. But, if I know it's something extremely serious, that's when I know I should go to the hospital." Participants also reported asking family members for medical advice and using home *remedios* (remedies), family members' medications, over-the-counter treatments, and traditional healers, including *curanderos* (traditional healers) and *sobadores* (traditional masseurs). When participants finally did seek medical care, they typically accessed public hospital emergency rooms and community clinics. For those enrolled in college, student health centers were also common sources of care. One focus group participant summarized his approach to medical care: "I see healthcare as ... the last resort, for when everything else doesn't work."

Barriers to accessing care. Study participants identified many barriers to health care access including cost, limited health care literacy, difficulty navigating health care logistics, and fear and mistrust of providers (Table 3).

Costs. Cost was the single most common barrier to health care. Participants reported that they frequently lacked the financial resources to pay for health care as it competed with other basic needs: "Do I want to spend \$40 or \$35 on the checkup, or do I want to spend it on food for myself or to pay for school or to pay for rent?" Insurance did not always alleviate this tension: "I had insurance from my dad growing up. But, even then, you still had to pay five bucks ... I tried avoiding going to the doctor or getting medicine because it's so expensive." Several participants also voiced worry about the large bills they could receive after seeking medical care and expressed fear that medical debt would diminish their opportunities for legal immigration. Access to care

Table 3

Health care needs and barriers to health care reported by Deferred Action for Childhood Arrivals–eligible participants

Health care needs and health concerns	Barriers to health care
• Mental health	• Cost
○ Depression	• Limited health care literacy
○ Anxiety	• Fear of deportation
○ Trauma	• Discrimination within the health care system
○ Delays in achieving developmental milestones of young adulthood	
○ Stress	
• Preventive care	
○ Vaccines	
○ Annual examinations	
○ Reproductive health care	
○ Nutrition counseling	
• Specialty care	
○ Dental	
○ Vision	

also cost the participants time, which they might otherwise spend earning money for their educations or to support their families.

Health care literacy. A lack of health care literacy limited participants' knowledge about their insurance options and where to seek health care. This limitation was often intergenerational because their families had little experience using insurance or navigating the health care system: "I guess my parents don't understand the system as well ... [That] affected me because I don't understand it, and there was nobody to teach me." Even participants who were fortunate enough to have employer-based coverage reported, "Some of us have health insurance and we don't have no idea what it actually covers." With limited experience navigating the health care system, participants expressed surprise and frustration with delays in getting appointments, long wait times, and a lack of provider knowledge about health care options for immigrants.

Fear and mistrust. Mistrust of doctors was commonly reported, with participants expressing concerns that doctors were only motivated by money and lacked understanding and sensitivity about their immigration status. One participant shared that doctors "don't really know much about the status and what it means, necessarily, so sometimes the alternatives that they offer ... don't work for you because you're not eligible for them." After interacting with a mental health provider, another participant explained, "even if I would share my story, they won't understand. You know, they're doing it for a business ... they're not doing it to listen to you." These concerns were multiplied by a fear that disclosing their documentation status could put their families at risk for deportation.

Participants also shared experiences of discrimination from health care providers: "I think it's related to like how we're brown, and we're undocumented, and we're low income ... They're going to treat you differently." Several participants also expressed that because the majority of DACA-eligible young adults lack a regular provider, they have few opportunities to develop trusting relationships that might increase their comfort level. Finally, participants discussed avoiding medical care out of fear that newly diagnosed health problems would limit their chances for citizenship or cause financial stress.

Health issues and health care needs

Mental health issues. Mental health issues, including depression, anxiety, trauma, substance abuse, and stress, represented the largest category of health problems reported, and these issues often went unrecognized. One participant explained, "I think a lot of things get normalized, so stress, anxiety, working 80 hours a week—that's normalized, right? ... I think a lot of folks are in deep depression, but ... don't realize it." On questionnaires, nearly a quarter of participants reported that within the past month, they felt so depressed that nothing could cheer them up; discussions highlighted early trauma and loss of family support systems as being related to depression. One participant recalled, "There's so much trauma in our community ... When other people talk about family, I don't know those feelings because my experience of having a family is that I had a really big family. They all loved me, and when I was nine years old, I had to leave and I never got to see them again."

Challenges in transition to adulthood. With limited family support systems and frequently untreated mental illness, DACA-eligible youth face great challenges in transitioning to adulthood. Many reported discovering their documentation status when seeking a driver's license, first job, or federal financial aid for college. One participant described her senior year in high school as a, "dark cloud over my head. Like I'm trying to do this, but at the same time I can't do this ... it's really stressful and it just gets to a point where like I'm starting to feel hopeless." Participants described this phase of life as "hitting the wall," characterized by limited opportunities despite years of dedicated studies. During this phase, many participants reported feeling torn between pursuing their educational goals and working to support their families who were frequently living in poverty without legal work permits. Several participants recalled feelings of hopelessness and thoughts of suicide, as they confronted the challenges limiting their ability to attain adult milestones, such as driver's licenses, college education, and employment.

Stress due to immigration status. Focus group participants reported high rates of stress related to financial insecurity, discrimination, and the legal and social challenges related to their immigration status. The DACA application process itself was tremendously stressful: "I remember I couldn't sleep when I was applying ... You have no peace in mind because these people are tracking your whole life ... what if my parents get deported like because of this information?" Participants reported that even receiving DACA offered limited relief because of its temporary nature and the continued struggles of undocumented family members.

Physical health issues and health care needs. Participants discussed a variety of physical health concerns including unhealthy changes in their diet and physical activity after immigrating. Some were aware of interactions between their mental and physical health: "When I get sad, I want to eat. When I want to eat, there's no money to eat something good. So it's fast food. So it's just like a chain of things that just lead to poor health." One participant explained that financial stressors limited his opportunities to engage in healthy living: "I don't have time ... to do exercise. It's not in my priorities because of work and family responsibilities that I have to take care of, lack of money, lack of transportation." Given these health concerns, participants wanted better access to preventative medical care, such as annual physicals, vaccinations, and reproductive health care. Participants also reported particular challenges accessing dental, vision, nutrition, and specialty care.

Resilience and risk-avoidance. Although DACA-eligible young adults were clearly at risk for mental and physical health issues, they also reported that their immigration status was inadvertently protective in some ways. The resilience of this population was demonstrated in their tenacious pursuit of academic achievement in spite of the economic, health, and social obstacles related to their immigration status: "I have to excel. I have to be the best I can be so I can prove that I belong here." Participants also reported confidence in their ability to solve problems in challenging situations: "I needed to find a way to progress pretty much on my own...I feel more empowered, like I did it by myself."

Although some participants reported that they were susceptible to unhealthy coping mechanisms such as substance use, most participants reported that their common fear of deportation and their desire to maintain their new legal status left them risk adverse. One participant explained that as immigrants without documentation, "We've always had to be careful. It's not a matter of choice. You can't drink ... you can't be out partying too much ... it's not going to go away just because I get an ID." Participants also discussed avoiding unprotected sex to limit contact with the medical system and subsequent bills. One participant explained that unlike US citizens, "I don't have the same space to take that kind of risk."

Deferred Action for Childhood Arrival's impact on access to care

Participants reported that while DACA improved their access to health care in some ways, many challenges remain. DACA may improve health care access by leading to employment opportunities with job-based insurance, the ability to obtain a driver's license which facilitates travel to health care, and providing temporary relief from the threat of deportation. One participant explained that he benefitted from "just having ID so that, when you go see a doctor ... you don't have to explain why you don't have a Social number."

Even with DACA, participants expressed uncertainty about their eligibility for benefit programs and a persistent fear of disclosing information to authorities and health care institutions. One participant reported, "The resources are not completely available, right? So if I need mental health, like I don't know where I'm supposed to go. Do I qualify for a certain kind of help because of my new status?" Participants also remained concerned about undocumented family members: "When I got it, DACA, I was feeling very conflicted ... Like, let's celebrate when we all have these resources."

Discussion

This study is the first to describe the health concerns and barriers to care for DACA-eligible young adults. In general, young adults have lower health care utilization and higher rates of certain negative health outcomes, such as sexually transmitted diseases and unintentional injury, than adolescents and older adults in the US [6]. This study indicates that for DACA-eligible young adults, many of whom have experienced trauma and long-term stress associated with their undocumented status, there are prevalent mental health concerns.

Although participants highlighted the profound, but unsurprising, mental health issues they faced, including depression, anxiety, and trauma, they also cited the challenges of obtaining health care in the context of their families and communities, where scarce financial resources place medical and mental health needs below food, shelter, and education. Novel to this study, DACA-eligible young adults highlighted that they lack opportunities to learn how to navigate and utilize health care and, thus, remain skeptical of the motives and financial gains of providers. The rift between DACA-eligible young adults and potential health care providers is further increased by system barriers such as long wait times and challenges determining eligibility for services. It was sobering to note that even in ethnically diverse urban centers in California, negative experiences with providers who lacked knowledge about the meaning of undocumented status or failed to provide culturally sensitive

care also contributed to barriers to health care. Finally, with or without DACA, participants reported a hesitation to interact with the health care system for fear that any health problem or medical debt might limit their ability to gain or maintain legal immigration status.

These barriers to care need to be addressed at the provider, community, and policy levels. This study suggests that culturally sensitive care is required to improve health care access for DACA-eligible young adults as a means of fostering confidentiality and trust, understanding the health needs of these immigrant youth, and offering acceptable and effective treatment options. At the provider level, health care professionals could benefit from education about laws regarding confidentiality for immigrants, trauma-informed care, and local health care and insurance options for immigrants without documentation. At the community level, education is needed to inform DACA-eligible youth and their families about their health care options as their access to health insurance shifts with changing state and federal immigration and health care policies. Improved awareness of health insurance options and expanded health care access through policy changes may promote utilization of care for DACA-eligible young adults. Education at the community level regarding provider confidentiality and the recently enacted US Immigration and Customs Enforcement policy, which states that those who seek Medicaid or Health Insurance Exchange enrollment will not face deportation, may help decrease fears about interacting with the health care system, and promote coverage among mixed status families [21]. In addition, fostering connections between health care providers and community-based advocacy groups could promote referrals to and from immigrant-friendly social services organizations. At the policy level, providers and community-based organizations can advocate for state and local governments to expand health care coverage to DACA recipients. California has already made a ground-breaking policy commitment to provide state-funded Medi-Cal to financially qualified DACA recipients [22,23].

Although innovative, this study had several limitations. Focus groups were only conducted in English and were held with Latino subjects in urban areas with high concentrations of eligible participants. This focus on Latinos is consistent with the majority Latino demographics of the DACA-eligible population [13]. However, it remains unclear if the health concerns and barriers to health care will be the same across other immigrant groups, such as Asians and Pacific Islanders. In addition, the use of snowball sampling and social networks may have led to a more highly educated sample. Despite these limitations, these results point to the depth of health care needs even among DACA-eligible young adults who may have greater access to resources than other undocumented immigrants. Further studies with additional immigrant groups and in other geographic regions are required to better understand the health care needs and barriers among the broader DACA-eligible population nationally.

Health care and immigration are two of the country's most rapidly changing policy areas. For the 1.8 million adolescents and young adults who qualify for DACA, the policy shifts occurring in these areas have the potential to create new health care access for this marginalized group. The DACA-eligible population represents a fraction of the 11 million immigrants living without documentation. Ultimately, further policy changes are needed in health care and immigration reform to expand access and improve health for legal residents and naturalized citizens [24].

Simultaneously, participatory research is needed to learn more about this underserved population and engage this community in designing research questions, recruiting participants, and validating and disseminating research findings [17]. Community engagement is also a key to developing new strategies, programs, and policies, regardless of the outcomes and timing of immigration reform. It is critical that public health professionals, health care providers, immigrants, advocates, and policy makers work together to improve health care access and address the health needs of this vulnerable, but resilient population that represents our country's future.

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