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Dreams deferred: Contextualizing the health and psychosocial needs of undocumented Asian and Pacific Islander young adults in Northern California

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A B S T R A C T

There are currently 1.5 million undocumented Asians and Pacific Islanders (APIs) in the US. Undocumented API young adults, in particular, come of age in a challenging political and social climate, but little is known about their health outcomes. To our knowledge, this is the first study to assess the psychosocial needs and health status of API undocumented young adults. Guided by social capital theory, this qualitative study describes the social context of API undocumented young adults (ages 18–31), including community and government perceptions, and how social relationships influence health. This study was conducted in Northern California and included four focus group discussions (FGDs) and 24 in-depth interviews (IDIs), with 32 unique participants total. FGDs used purposeful sampling by gender (two male and two female discussions) and education status (in school and out-of-school). Findings suggest low bonding and bridging social capital. Results indicate that community distrust is high, even within the API community, due to high levels of exploitation, discrimination, and threats of deportation. Participants described how documentation status is a barrier in accessing health services, particularly mental health and sexual and reproductive health services. This study identifies trusted community groups and discusses recommendations for future research, programs, and policies. © 2017 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

1. Introduction

The Patient Protection and Affordable Care Act (ACA) promises to expand health coverage to an additional 32 million individuals but leaves out an estimated 11.3 million undocumented immigrants (Krogstad et al., 2017). Although the percentage of uninsured Americans dropped to historic lows under the ACA, nearly 40% of undocumented immigrants still remain uninsured (Fabi and Saloner, 2016). The lack of social services and access for undocumented immigrants run in contrast to their contributions to the U.S. economy. In 2010 undocumented workers contributed as much as $13 billion in payroll taxes to social security, but received only $1 billion in benefits (Gross et al., 2013).

A federal program known as Deferred Action for Childhood Arrivals (DACA) changed the landscape of healthcare options for undocumented young adults. The Obama Administration established DACA in 2012 with 1.2 million young adults eligible for the program. This policy defers deportation and grants a work permit and temporary Social Security Number for eligible undocumented young adults. Although the DACA program is not a pathway to citizenship, the legal status it provides allows for participation in the healthcare exchanges. For undocumented young adults, navigating critical life milestones such as applying to college, entering the workforce, or obtaining driver’s licenses, pose unique political challenges from those who migrate as adults (Gonzales et al., 2013). The inability to legally work, receive financial aid for college, drive, and obtain health care are constant stressors (Suárez-Orozco et al., 2013).
Moreover, the last few years have marked a significant demographic shift in which Asian and Pacific Islanders (APIs) are now the fastest growing immigrant population in the US (US Census Bureau, 2011), including 1.5 million undocumented APIs (Migration Policy Institute, 2015), 29% of whom live in California (Wallace et al., 2012). Undocumented immigration from Asia has tripled from 2000 to 2013, with the number of undocumented immigrants from China, Korea, and India increasing four-fold, eight-fold, and ten-fold, respectively. The impetus for migration from Asia varies greatly, ranging from education and employment to family reunification. While processes by which API immigrants become undocumented have not been fully elucidated, contributing factors include problems arising from family and employment sponsors (Rosenblum and Soto, 2015). Despite the rapid growth in immigration, little is known about the unique challenges undocumented API young adults face in the current literature. Among API immigrants in general, studies find they are less likely to use mental health services due to stigma, and are less likely to use mental health services compared to their US-born counterparts (Abe-Kim et al., 2007). Much less is known about API undocumented young adults and their psychosocial health needs.

Research (particularly needed to examine the health of undocumented APIs, particularly as these young adults are coming of age and transitioning to adulthood in a challenging social and political context. While they seek to develop identities as part of normative adolescent developmental processes, critical milestones in their lives are precluded due to their documentation status (Gonzales et al., 2013).

1.1. Linking social and community contexts to health among undocumented: social capital theory

We adopt social capital theory to examine the social and community contexts of undocumented API young adults and the influence on health. Social capital is defined as the resources that people access through their networks and social relationships (Berkman and Kawachi, 2000). Social capital theory is an important lens through which to examine health among undocumented populations given that the strength of social ties are particularly important for migrant populations (Aguilera and Massey, 2003; Massey, 1987). Social capital and social ties are strong predictors of health and access to healthcare (Kawachi and Berkman, 2001). Factors such as community cohesiveness, familiarity, and trust facilitate the spread of health information, with the ability for health norms to be adopted more quickly in tight social networks (Rogers, 2010).

Different types of social capital include bonding, bridging, and linking social capital (Szreter and Woolcock, 2004). First, “bonding” social capital refers to the resources derived from social networks between similar groups of people (i.e. class and race). While this may provide a sense of solidarity, it may also reproduce social disadvantage depending on the resources and norms in the community. Disadvantaged communities, for example, may rely on one another for support; however, if youth are only exposed to other poor neighbors, it may result in communities feeling “trapped.” On the other hand, “bridging” social capital refers to the resources accessed across networks that cross class, race/ethnicity, or other social characteristics. Bridging social capital is generally associated with better health outcomes, including increased access to health information (Putnam, 1995). “Linking” social capital is defined as social ties between individuals with differing levels of power. Neighborhood institutions serve as important examples of linking social capital, such as community-based organizations, and across generation from elderly to youth organizations (Fried et al., 2004; Glass et al., 2004).

Berkman and Kawachi (2000) suggests three potential mechanisms for which social capital may influence health: 1) influencing health-related behaviors, by promoting rapid diffusion of health information or adoption of healthy norms; 2) access to services and amenities; and 3) affecting psychosocial processes, such as social support and social engagement. For the undocumented community, social capital may be limited. Social stigma, fear related to deportations, and factors such as occupational exploitation may all lead to increased social isolation and loss of social capital for the undocumented (Hagan et al., 2015).

Intersections of race, culture, and immigration may produce disparities between different undocumented communities in relation to social capital. For example, APIs are less likely to apply for DACA compared to other populations – 21% application rates of eligible Asians compared to 77% of Latinos (Rusin, 2015). Community-based organizations and legal service providers in API and Latino immigrant communities have attributed this disparity to API’s increased sense of shame and stigma, loss of status within their communities due to their documentation status, and mistrust in governments (Rusin, 2015). Undocumented young adult Latinos, on the other hand, have been found to have high community social support (Siemons et al., 2016). Undocumented immigrants, and APIs in particular, live in the shadows of society, and there is a need to better understand how social ties to families and communities impact health access and status.

Guided by social capital theory, this paper seeks to understand how social and community contexts influence health for undocumented immigrants. This study assesses both the potential positive and negative influences of social relationships due to documentation status. We explore the limits and possibilities of social capital to overcome rigid and political barriers to care. This study, to our knowledge, will be the first study to contextualize the health status of API undocumented young adults.

2. Methods

The manuscript uses data from the BRAVE Study (Building community Raising API Voices for health Equity), which includes qualitative data, including focus group discussions (FGDs) and in-depth interviews (IDIs). The purpose of the study was to examine the health status and health needs of undocumented APIs and how DACA influences health access and behaviors. This study was guided by principles of community-based participatory research (CBPR) by developing a Community Advisory Board (CAB) and engaging three interns from the community to assist all research activities, including participant recruitment (Wallenstein and Duran, 2006). Eight CAB members, representing community institutions such as universities, policy organizations, undocumented youth organizations, and community health services, contributed to the design of the study and supported development of field guides and interpretation of data.

In total, the BRAVE Study conducted four focus group discussions (FGD) and 24 in-depth interviews (IDI) between October 2015 and March 2016, with 32 unique study participants.

2.1. Study participants and recruitment

Four FGDs (n = 16) used purposeful sampling by gender and education status (in school/out of school) in order to provide more homogenous groups, allowing for greater group discussions (Ulin et al., 2004). Past studies have found that school vs. work environment changes the undocumented immigrant experience, with school mostly being a safe space while work environments can be discriminatory (Abrego, 2011). We recruited participants for IDIs
from those who participated in FGDs as well as individuals who were not able to attend a scheduled FGD. Sampling IDIs from the FGDs was also strategic — another study conducted among migrants found that this sequence helped establish a connection between the interviewer and participant and helped participants feel more comfortable in discussing more sensitive topics (Sudhinaraset et al., 2012). In total, we conducted 24 IDIs.

Guided by our CAB and study interns, we used a number of recruitment strategies to identify study participants. Recruitment strategies included passive approaches (i.e. community flyers, study website, Facebook page) and active approaches such as venue-based recruitment in which researchers recruited potential participants from community venues (i.e. legal offices, community-based organizations, universities, health centers, etc.), snowball sampling (participants recruiting other potential participants), and social networks (i.e. study interns from community identified potential study participants). At the start of the project, CAB members helped to identify key stakeholders and community-based organizations (CBOs) known to work with undocumented API young adults. We used this list of organizations and key stakeholders to conduct recruitment activities. Trusted community leaders (e.g. college counselors for undocumented students, immigrant youth organization directors, etc.) helped advertise and recruited for the study through email and word-of-mouth.

Study eligibility included individuals who were: 1) between the ages of 18–31 year; 2) identify as Asian/Pacific Islander; 3) undocumented (including DACA-eligible, DACA-ineligible, and DACA-recipients); and 4) comfortable participating in an interview or group discussion conducted in English. Study recruitment took place in the Northern California area and all participants were screened prior to participating in the study.

2.2. Data collection

To provide an environment for participants to speak comfortably about their experiences, FGDs were held at undocumented youth centers at universities for in-school youth and an undocumented youth organization for out-of-school youth. IDIs were held in a private location that was convenient for the study participant. Participants filled out a demographic form at the beginning of all FGDs and IDIs. Verbal informed consent was obtained from all study participants before initiation of the FGDs and IDIs, and researchers also obtained consent for these sessions to be audio-recorded and for the study staff to take notes. Before FGDs and IDIs, a study staff explained in detail the purpose of the study, what the information collected would be used for, that all responses and audio recording would be de-identified, and that all participants may feel free to stop at any time if they feel uncomfortable. Study staff also informed participants that they would still receive an incentive even if they did not consent to be audio-recorded. All study participants agreed to be audio-recorded.

A facilitator and note-taker conducted the FGDs. At the beginning of the group discussion, participants were informed about the rules for the discussion, focusing particularly on respect and confidentiality of responses. FGDs lasted approximately 1.5–2 hours. IDIs lasted approximately 60–90 minutes. All study participants received a $40 gift card for participating.

Separate field guides were used to conduct FGDs and IDIs and included questions regarding DACA, the undocumented immigrant experience, and healthcare access. [see Table 1]. We included questions about community resources and social support available for participants. These questions informed the inductive development of social capital theory used to frame this manuscript (Strauss and Corbin, 1998). The use of both FGDs and IDIs is purposeful — while FGDs are used to describe cultural normative patterns of behaviors among groups, IDIs are used to explore more sensitive topics in order to maximize privacy (Ulin et al., 2004). In FGDs, participants may be able to relate to one another and bring up topics that they would not otherwise feel comfortable in a one-on-one situation. Themes covered during interviews were developed from a previous similar study on Latino populations (Raymond-Flesch et al., 2014) and from formative key-informant interviews with 12 key stakeholders. All audiotapes were transcribed for analyses.

2.3. Analyses

Four trained researchers coded all FGDs and IDIs using an iterative and collaborative process. A combined thematic analysis and grounded theory was used to conduct qualitative data analyses (Strauss and Corbin, 1998). Thematic analysis method focuses on organizing and describing rich qualitative data by coding all the data into themes (Ulin et al., 2004). The four researchers first developed a coding scheme and collaboratively and iteratively finalized the codebook based on emergent themes based on grounded theory. Coders used open and axial coding. Interpretation of data included comparing theme frequencies, identifying theme co-occurrences, and discussions with the research team. Based on grounded theory, we allowed for themes and categories to emerge and inductively developed a theory to explain these findings. Social capital theory emerged as a useful theory to explain API undocumented youth experiences and psychosocial health. We used participant based group analysis, a technique that allows individual participants to be separately analyzed within a broader discussion (Ritchie et al., 2013). An advantage of this approach is that it allows participant information from FGDs to be separately obtained while also taking note of group dynamics. Additionally, major themes were also presented to CAB members and undocumented young adults to validate and explain study findings. All analyses were conducted using Atlas.ti software.

All study documents and procedures were approved by the University of California, San Francisco Institutional Review Board.

3. Results

3.1. Section one: social stressors, community distrust and fear of deportation

3.1.1. Characteristics of study participants

The study population was comprised of 32 unique participants from four FGDs and 24 IDIs (Table 2). Half of the population was male and the average age was 22.9 years (SD 3.3). All participants were high school graduates with 40.6% having a college degree or higher. Almost all participants (90.6%) have lived in the US for over ten years, and most moved into the country with their family (59.4%) for work (46.9%) and/or educational opportunities (43.8%). The top two countries of birth for participants in this study were South Korea (34.4%) and Philippines (21.9%) (Table 3). The majority of our study population was either a DACA-recipient (87.5%) or DACA-eligible (6.3%); the rest were DACA-ineligible (6.3%).

3.1.2. Low bonding social capital: community distrust, stigma, and social isolation

While many participants and their families found themselves undocumented on overstayed tourist and work visas, stories of failed petitions and outright labor exploitation were frequently a part of undocumented immigration experiences. This resulted in distrust of communities, institutions, and even family members. One participant recounted how her father left Singapore for work in Baltimore that promised sponsorship for him and his family, only to realize...
Table 1
Selection of questions from Table 1

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Documentation Status</strong></td>
<td></td>
</tr>
<tr>
<td>What does documentation mean to you? (FGD)</td>
<td></td>
</tr>
<tr>
<td>When did you first find out about your documentation status? (IDI)</td>
<td></td>
</tr>
<tr>
<td><strong>Health Status and Healthcare Access</strong></td>
<td></td>
</tr>
<tr>
<td>Where do you think that DACA-eligible and other undocumented young adults first go to get health care? (FGD)</td>
<td></td>
</tr>
<tr>
<td>What barriers exist that might prevent DACA-eligible or other undocumented young adults from seeking care? (FGD)</td>
<td></td>
</tr>
<tr>
<td>What do you do if you get sick? (IDI)</td>
<td></td>
</tr>
<tr>
<td>Are there specific health challenges that you have faced? (IDI)</td>
<td></td>
</tr>
<tr>
<td><strong>Community Resources</strong></td>
<td></td>
</tr>
<tr>
<td>Are there particular programs in your area that serve immigrants without documentation? (FGD)</td>
<td></td>
</tr>
<tr>
<td>If there were a situation where you couldn't treat yourself, what would you do first? Where would you go? (IDI)</td>
<td></td>
</tr>
<tr>
<td><strong>Social Support</strong></td>
<td></td>
</tr>
<tr>
<td>What do you think are the differences in how health care providers treat undocumented young adults, DACA-eligibles and other youth? (FGD)</td>
<td></td>
</tr>
<tr>
<td>Have you had questions regarding your health? Where did you seek help? (IDI)</td>
<td></td>
</tr>
<tr>
<td>With whom do people your age feel most comfortable discussing health information? (IDI)</td>
<td></td>
</tr>
<tr>
<td>What do you think are the differences in how health care providers treat undocumented young adults, DACA-eligibles and other youth? (FGD)</td>
<td></td>
</tr>
</tbody>
</table>

Table 2
Characteristics of the BRAVE Study population.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>16 (50.0)</td>
</tr>
<tr>
<td>Female</td>
<td>16 (50.0)</td>
</tr>
<tr>
<td><strong>Age, mean (SD)</strong></td>
<td>22.9 (3.3)</td>
</tr>
<tr>
<td><strong>DACA status, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Recipient</td>
<td>28 (87.5)</td>
</tr>
<tr>
<td>Eligible (not a recipient)</td>
<td>2 (6.3)</td>
</tr>
<tr>
<td>Ineligible</td>
<td>2 (6.3)</td>
</tr>
<tr>
<td><strong>Highest level of education completed, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>19 (59.4)</td>
</tr>
<tr>
<td>College or higher</td>
<td>13 (40.6)</td>
</tr>
<tr>
<td>Mother's education level, n (%)</td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>7 (21.9)</td>
</tr>
<tr>
<td>High school</td>
<td>10 (31.3)</td>
</tr>
<tr>
<td>College or higher</td>
<td>15 (46.9)</td>
</tr>
<tr>
<td><strong>Household yearly income, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;$10,000</td>
<td>3 (9.4)</td>
</tr>
<tr>
<td>$10,000-$19,999</td>
<td>4 (12.5)</td>
</tr>
<tr>
<td>$20,000-$29,999</td>
<td>6 (18.8)</td>
</tr>
<tr>
<td>$30,000-$39,999</td>
<td>4 (12.5)</td>
</tr>
<tr>
<td>$40,000-$49,999</td>
<td>6 (18.8)</td>
</tr>
<tr>
<td>$50,000-$59,999</td>
<td>2 (6.3)</td>
</tr>
<tr>
<td>$60,000-$69,999</td>
<td>2 (6.3)</td>
</tr>
<tr>
<td>$70,000-$79,999</td>
<td>3 (9.4)</td>
</tr>
<tr>
<td>$80,000+</td>
<td>2 (6.3)</td>
</tr>
<tr>
<td><strong>Length of stay in the US, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>5–10 years</td>
<td>3 (9.4)</td>
</tr>
<tr>
<td>10+ years</td>
<td>29 (90.6)</td>
</tr>
<tr>
<td><strong>Reasons for immigrating, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Moved with family</td>
<td>19 (59.4)</td>
</tr>
<tr>
<td>Moved for family's work/labor opportunities</td>
<td>15 (46.9)</td>
</tr>
<tr>
<td>Moved for education</td>
<td>14 (43.8)</td>
</tr>
<tr>
<td>Moved to live near other family</td>
<td>4 (12.5)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (9.4)</td>
</tr>
</tbody>
</table>

Table 3
Country of birth (n = 32).

<table>
<thead>
<tr>
<th>Country</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Korea</td>
<td>11 (34.4)</td>
</tr>
<tr>
<td>Philippines</td>
<td>7 (21.9)</td>
</tr>
<tr>
<td>China</td>
<td>2 (6.3)</td>
</tr>
<tr>
<td>Indonesia</td>
<td>2 (6.3)</td>
</tr>
<tr>
<td>Other Asian/Pacific Islander country</td>
<td>6 (18.8)</td>
</tr>
<tr>
<td>Other non-Asian country</td>
<td>4 (12.5)</td>
</tr>
</tbody>
</table>

that they were the victims of labor exploitation:

He [the employer] never really applied for any visas for our family. So we basically became undocumented … Every time he would ask for documentation or social [security number] … his boss would be like, “You're not even here,” like you know, “according to the law I can call the police, I can like deport you all. Throw your kids in jail.” (Female, DACA-recipient, out-of-school FGD)

A number of participants noted similar experiences of coercion and exploitation at the hands of employers, community members, and even church administrators. Immigrants and their families in these situations were especially vulnerable since staying in the U.S. meant that they would become undocumented, while leaving the country on an overstayed visa would prevent them from returning to the U.S. indefinitely.

These experiences have profound impacts on social networks. One participant noted how these types of experiences shaped both his and his family's social network:

My mom already told me … don’t talk to other Filipinos, they'll take advantage of you … And I still don't have any like close Filipino friends like now … they know people who got taken advantage of by other Filipinos. There’s also a big stigma for being undocumented … There’s just a natural distrust of other Filipinos for the most part (Male, DACA-recipient, IDI)

Especially for undocumented parents who do not speak English as a primary language, silence and isolation are the consequences of these traumas and constitute a barrier to seeking services and resources in their communities.

Moreover, many participants described how they grew up with internalized feelings of “shame” because of their documentation status. This difference left many feeling isolated, particularly during the middle and high school years:

Just knowing from such a young age that I held this secret about myself that I wasn’t supposed to tell someone … I already felt very disconnected from people. Like very isolated … I just always felt different and I couldn’t relate to my peers … and that just only got worse as I went through middle school and high school. (Female, DACA-recipient, IDI)

For undocumented young adults, the inability to participate in
common rites of passage between adolescence and young adulthood had increasingly profound impacts on their self-perception and material realities. Particularly, being unable to access financial aid and higher education crippled both self-esteem and hopes for the future. Yet, these individuals felt isolated and unable to approach friends or other resources in their communities.

3.1.3. Constant stress and fear of deportation

The high stakes of being undocumented were a constant source of fear and stress for undocumented young adults and their families. As more policies and legislation open doors for undocumented young adults, these new opportunities can also be catalysts for contentious family dynamics. A participant who reached out to his high school guidance counselor about DACA remembers: “My parents got so upset ... they just yelled at me all night. They said 'if because of this one mistake we have to get deported ... know that this is on your conscience'” (Male, DACA-recipient, IDI). The participant later learned that his parent’s vehement response had been conditioned by the trauma of being blackmailed by members of the Korean community. If members of their own community could betray them, his parents felt that the government was certainly not to be trusted.

The fear of deportation has a powerful effect on the everyday lives of undocumented young adults and shapes the trajectory of their growth and development:

[Due to the] fear of deportation ... my main personal issue was that I was not able to ... plan things ... It was just more like daily things. ‘Cause I just had no idea when I would be deported ... plus you don’t know if you’re gonna get a job after. (Male, DACA-recipient, IDI)

Six out of 32 participants (18.8%) have either faced deportation proceedings themselves or have had immediate family members who have been deported. This includes two participants with one or both parents who were deported, and four additional participants who themselves entered deportation proceedings but were not deported. One young woman describes the trauma of her mother’s deportation. At the time, she was in her first year of community college, sharing the same room with her mother, when law enforcement officials “ barged” into their house in the middle of the night:

There were lots of flashlights beamed and shined in our faces really aggressive like ‘get up’ ‘put your clothes on’ ‘come outside’ you know making us sit on our couches being really aggressive treating us like criminals in our own house ... And I remember just kind of feeling like ... a really little kid again. I think I was just really scared and confused and I remember just sitting there and I just broke out into tears and just crying. (Female, DACA-recipient, IDI)

The traumatic experience, including separation from her mother, left this young woman severely depressed. She eventually sought care for mental health services and applied for and received DACA. This story is reflective of other undocumented young adults who have constant fears that they or their family members will be deported. In mixed status families, even if a young adult receives DACA, the constant fears of deportation do not subside because their families may still be targeted.

3.1.4. Bridging and linking social capital: community resources, organizing and empowerment

Despite the challenges participants faced as a result of their documentation status, some noted feelings of empowerment as they learned to become proactive and more involved in their communities. A key component to this process is CBOs that serve as safe spaces where these individuals can gather, be heard, and belong. In these places, individuals form bonds with others that not only help them feel more connected with the community but also motivate them to do more for others. One participant described his experience in joining one of these organizations:

...that was like the most uplifting time of my life. ‘Cause now I found like a group of people who are in the same [situation]. They are all college students and I’m like a worker but at the same time like they all came from somewhere else and were all stuck in this non-status situation ... We’re like, “Alright we’re all stuck in this same situation. Let’s fight. Let’s do it.” And so I definitely felt more secure, more safe, and more energy to do what was right. (Male, DACA-recipient, out-of-school FGD)

Participants also described how belonging to an organization also helped them feel empowered and protected:

Having a space like [organization], it really saved me from going through depression ... after I got my deportation date, after my meeting at ICE office February of 2012. [Organization said] ‘we got your back, if anything happens, we got your back’ ... they saved me ... (Female, DACA-recipient, out-of-school FGD)

This involvement and motivation is critical, particularly for communities where social capital is low and undocumented individuals lack the trust and resources they need. They seek to change this by “breaking isolation” and encouraging others to become more informed and to seek help when needed.

3.2. Section two: what are the health needs of undocumented API young adults?

Participants describe how social ties may lead to worse health outcomes potentially through three mechanisms: 1) low utilization due to limited access because of documentation status and fear of accessing services; 2) low levels of health information due to limited social networks; and 3) increased stress and poor health status due to social isolation.

3.2.1. Barriers to access to care: documentation status

Distrust in communities also led participants to be less likely to access health services. The constant fear of deportation was reflected in participants’ disengagement in health care settings. One participant said:

One time when I was biking and I got hit by a car ... they just hit me and I flew like 10 feet away from the place of impact ... and this family they were like, ‘oh don't worry, we called the ambulance, they should be coming.’ But for me I was too scared. I was like oh my god, I don't wanna get deported. Like if I go to the hospital they're gonna need- they're gonna ask me all these question[s]. So I ended up leaving the place. (Male, DACA-recipient, IDI)

The lack of affordable healthcare options stemming from their immigration status resulted in many participants describing healthcare as a “privilege” and preventative care as “selfish.” For these participants, the sacrifices family members have made take financial and obligatory precedence over personal needs. Because parents and other family members have risked much to live in the
US, taking care of only oneself was internalized to be indulgent. Especially in Asian Pacific Islander families, you come as an undocumented student your main focus is like, school, or work. And there’s not much time to really think about yourself. Because you’re kind of on survival mode. Like, I have to do this for my family. This is what we came here for, we didn’t risk our lives for me to sit around and be selfish and think about myself, to do yoga. (Female, DACA-recipient, in-school FGD)

Despite being aware of their health needs, participants reported that it was common in their families to not seek care “until you’re dying pretty much” secondary to financial and deportation concerns (Female, DACA-recipient, out-of-school FGD). Instead of using formal health services, the most common sources of health information were Internet sources (e.g. WebMD, Mayo Clinic), friends, and family. Participants had mixed opinions on using Internet sources, with some reporting these sites to be untrustworthy while others referred to them (i.e. WebMD) as “the undocumented primary care” (Female, DACA-recipient, out-of-school FGD).

3.2.2. High mental health needs

Trauma and stressors related to documentation status resulted in significant mental health issues among study participants. Nineteen people (59.4%) reported mental health challenges and twelve reported being diagnosed with or having symptoms of depression. One participant reported cutting and three reported suicide attempts. Participants framed their mental health in the context of their documentation status and the related challenges and trauma they faced:

I was pretty depressed for a while in college. Especially when I was going through all this [deportation proceedings]. I actually had to withdraw for a quarter because they [ICE] wouldn’t let me go back to school … I also had an ankle monitor at one time, which is possibly the worst thing that’s come out of all this … that’s something I continue to struggle with. (Female, DACA-recipient, IDI)

Addressing issues related to mental health in API undocumented young adults is further complicated by stigma that often highlights generational and cultural gaps between immigrant parents and their children. This stigma plays a major role in preventing participants from seeking and accessing services and resources. One participant describes the limits of social/familial connections in facilitating access to services:

I’ve had a lot of struggles with my mental health. I haven’t really received that many mental health services … I remember trying to tell my mom about it, that I was having feelings of contemplating suicide and feelings of isolation … the panic attacks … she would discourage me from seeing a therapist … She told me … I had to be stronger, more mentally strong … she said that if I went to a therapist then … they might think I’m crazy and institutionalize me or it would affect my employment prospects in the future. (Male, DACA-recipient, IDI)

Because parents are often fearful of institutions, they discourage participants from also seeking services. In our study, culturally competent mental health services were frequently mentioned as the most needed health service. Among participants who had previously used mental health services, many reported difficulty explaining their situation to providers. The lack of immigrant health awareness among mental health providers compromised the value of these services for undocumented APIs. Participants in one focus group mentioned the inaccessibility of mental health services for undocumented immigrants and, when asked whether having a therapist growing up would have been beneficial, they answered:

Essentially it would’ve been great to maybe have one [a mental health specialist] … but also especially one that understands the immigrant perspective. It’s so hard to talk to a teacher, an adult, about your status and they don’t know anything about what’s happening … you’d get teachers or counselors to say ‘why don’t you go back to your country then.’ (Female, DACA-recipient, out-of-school FGD)

In this example, legal status hinders young people from drawing on their social relationships for much needed support. Even in the context of connections to teachers, adults, and other counselors, their legal status prevents the undocumented from translating these relationships into resources that could be leveraged to support them in seeking mental health services.

3.2.3. Sexual and reproductive health needs

During in-depth interviews, 17 of 24 (70.8%) participants reported being sexually active, underlining the importance of sexual and reproductive health services in this community. Many participants found it difficult to access reproductive health services, particularly obtaining contraceptive methods. Of note, some participants also described how documentation status deterred people from becoming sexually active, with one participating saying: “I think being sexually active as undocumented is scary. Just the chances of you getting pregnant. Not everyone is lucky enough to get birth control.” (Female, DACA-recipient, in-school FGD).

Of the 17 people who reported being sexually active, the majority described barriers to accessing contraceptive services, including not understanding where to obtain services. One woman remarked on her reluctance to provide personal information as one of these barriers:

I was always very nervous about leaving my information … like omitting the social security … it is hard because it’s a sliding scale based on income so … I don’t really know if they’re gonna pressure me to provide more information. This is an institution you know. It’s very, very nerve-wracking to go. [Because of this] I never really thought about reproductive health in a way that was preventative. (Female, DACA-recipient, IDI)

While male participants did report being sexually active, there was noticeably less discussion around reproductive health.

3.3. Trusted providers and community partners

Sources of social support came from counselors at school, other undocumented friends, family members, and community-based organizations. Study participants described culturally-appropriate services related to mental health and sexual health. This was the case for one woman who finally received care that met her needs after visiting a number of mental health providers:

[Counselor is] Latino. She’s also LGBTQ. And undocumented. She’s just for undocumented students I think and she’s great. I feel like I could connect with her on a much more human level. There’s a professionalism there always but she’s much more … personable to me personally … I don’t feel the need to censor myself with her, like she’s just a little more like understanding of my kind of life and where I’m at. (Female, DACA-recipient, IDI)
In overcoming barriers to reproductive health, one woman explained why she traveled across state lines, back to her previous school, in order to obtain contraception from a prior “trusted” provider:

Well I felt like she wasn’t judging. She was just having a very honest open dialogue with me and trying to help me, inform me of my choices and my options and not really pressuring me to make decisions about my health. (Female, DACA-recipient, IDI)

Both participants in school and out-of-school indicated trusted community providers as life-lines, serving as a source of social and emotional support as well as creating a safe space for discussions. Despite significant barriers to accessing care, these stories highlight how young people continue to receive support through CBOs and trained health providers.

4. Discussion

This study, to our knowledge, is the first to examine the healthcare challenges and needs of API undocumented young adults. Results suggest that there is low bonding social capital in the API community directly from their documentation status, which may in turn influence health. Where previous work observed cultural themes of shame, stigma, and mistrust among undocumented APIs through personal anecdotes and word-of-mouth from immigrant activists and community service providers (Migration Policy Institute, 2015), the findings of this study corroborate and further elucidate these observations through the voices and experiences of API undocumented young adults. Long-term stressors highlighted in this study include constant intra-ethnic exploitation, reduced access to services, fears of deportation, and social isolation leading to high mental health problems. Long-term stressors play an integral role in the vicious cycle that perpetuates mistrust, isolation, and silence.

The results suggest a number of mechanisms in which social capital may influence health among undocumented API young adults. First, our findings suggest that documentation status itself served as a significant barrier in accessing health services, including reproductive and preventative care. This finding was reflected in another study comparing three groups of immigrant women (undocumented, documented, and refugee claimants), which identified documentation status as the single most important factor, not only in accessing services, but also women’s experiences in the quality of care received (Campbell et al., 2014). Lack of trust in the government and health care settings are barriers to accessing care, particularly for minority populations (Whetten et al., 2006). Understanding immigration experiences in accessing services and quality of care is important in determining health status and outcomes. Results suggest that barriers in accessing services included fears of being reported by healthcare providers as undocumented young adults have little experience with navigating health systems.

Numerous studies have highlighted the importance of social capital in immigrant integration, including increasing access to resources, employment opportunities, and emotional and cultural support (Aguilera and Massey, 2003; Hagan, 1998). For example, new immigrants settling in long-established and strong networks integrate into US more fluidly than poorly developed networks (Aguilera and Massey, 2003). Strong social networks provide migrants with emotional support and resources (Ryan et al., 2008). Results from this study suggest fragmented social networks within the API undocumented community. In particular, study participants described both low bridging and bonding social capital and varying degrees of linking social capital. Like other immigrant groups, participants in our study described intra-ethnic support networks at first settlement in relation to their parent’s employment; however, experiences of labor exploitation and bribes requested from “trusted support” persons for visas created intra-ethnic tension. This general mistrust within the API community, even within their own ethnic groups, decreased bonding social capital and led to feelings of social isolation among young adult APIs. This is in stark contrast to studies among undocumented Latino young adults populations that found strong peer support (Siemons et al., 2016) and strong social solidarity among broader Latino immigrant populations (Hoyt, 2009).

It should be noted that social capital may change over time—weakened and strengthened in response to broader political and social milieu. To disentangle how social capital may change, there is a need for deeper understanding of what contributes to strong vs. weak networks. Scholars suggest that while kinship-based networks help new immigrants integrate into the US, lack of material resources within ethnic community and uncertainties in the local economy may weaken network effectiveness over time (Menjivar, 1994). Social relationships should not only be viewed as one of support and cohesiveness; rather, social contacts may result in tension and frustration by immigrants negotiating challenging contexts (Menjivar, 2006). Future studies should assess how networks influence health among undocumented communities, including how these changes may occur in response to economic and social trajectories of the community.

Moreover, bridging and linking social capital are particularly important for social inclusion, even though they may result from weak social ties (Putnam, 1995). This includes social ties that cross race/class (bridging social capital) or institutions (linking social capital). APIs discuss a general mistrust of institutions—including churches, work, and government. While schools may serve as a respite for some participants, there was a general sense of mistrust of authority figures when discussing documentation status issues. This construct also carried into interactions of undocumented young adults with healthcare. Many participants did not have a clear understanding of what services or resources they had access to with their health insurance, resulting from both lack of health literacy and fear of interacting with health institutions. It is possible that the lack of trusted authority figures, including teachers and providers, may limit the quality health information that young adults receive.

On the other hand, linking social capital was extremely critical for a subset of participants who joined youth organizations that resulted in a sense of empowerment. A small, but growing literature highlights the importance of community-based organizations (CBOs) as resource and health brokers, particularly for individuals living in high poverty neighborhoods where social ties may not provide the adequate information or opportunities needed for young people (Small, 2009). While bonding social capital may be low among API undocumented young adults, CBOs and other safe spaces can serve as much-needed exceptions that allow individuals to connect with one another.

This study is not without limitations. First, because this is a qualitative study, these findings may not be generalizable to all API undocumented individuals due to small sample size leading to limited representation across the diverse demographic and other categories. However, there are limited data on the API undocumented population, and we attempted to interview both individuals attending school and out-of-school to obtain multiple perspectives. The population is also defined to individuals in urban areas with a high concentration of API populations. Future studies are needed to quantitatively assess health status, particularly mental health, across a broader geographic range. Due to the small sample, we are also not able to assess differences across ethnicity
and countries-of-origin among API populations or stratify our focus group discussions by these characteristics. A number of different economic, social, and cultural undercurrents have produced the histories of movement and migration of undocumented APIs in the U.S. Both similarities and differences abound in the personal narratives of immigration shared by participants, and it is important to recognize the heterogeneity in the population. Future work is needed to assess ethnic differences across API populations in terms of migration histories and health care status. Finally, while we attempt to recruit undocumented young adults who are not in school, many were tied to CBOs. Therefore, there are populations who are further marginalized and may face even greater levels of social isolation. These are the communities where targeted outreach may be most needed.

As a first step, our study highlighted a number of recommendations that are needed to support API undocumented young adults in the community, healthcare setting, and policy levels. This study suggests that active community outreach and education is needed, particularly to target hard-to-reach populations, such as young adults who may not be eligible for DACA as well as undocumented parents and older family members. Parents and older family members may have even less social capital because of limited participation with institutions such as schools and formal employment. CBOs may serve as brokers between undocumented and documented API communities to promote a greater sense of belonging and understanding within populations. Community outreach and legal services should be offered to undocumented families who may be experiencing exploitation or coercion. Community resources are especially needed in the healthcare setting, as our findings suggest the need for culturally appropriate services. Prior work studying undocumented immigrants shows that these individuals often prefer healthcare delivered through CBOs, particularly those that offer services regardless of identification (Campbell et al., 2014). Culturally appropriate services guided by community stakeholders can help promote the understanding of health issues of undocumented young adults, along with recognizing specific concerns related to API populations. A previous study on undocumented Latino immigrants show that health professionals should consider cultural factors when treating these individuals and that addressing psychosocial stressors in a proactive, supportive, and informative approach allows immigrants to be more receptive to care (Carmela Perez and Fortuna, 2005). Providers, community key stakeholders, and organizations should be educated on legal options for undocumented health care, including eligibility for health insurance programs, culturally sensitive services, and laws regarding confidentiality. At the policy level, strong leadership is needed to expand relief programs to all undocumented immigrant populations, including parents and older cohorts. While limitations remain with DACA, the policy has been shown to increase access to health care, human capital and social networks through CBOs, increased wages and earnings (Gonzales and Bautista-Chavez, 2014). Combined, leadership, data, and evidence-based policies are needed to support undocumented API communities to achieve healthy and productive lives.

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