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# The Health Needs of Undocumented Older Adults:

A view on health status, access to care, and barriers

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POLICY BRIEF



## EXECUTIVE SUMMARY

An estimated 3 million undocumented immigrants reside in the state of California. Undocumented older adults do not qualify for public benefits, including health care, even though many pay taxes. Health for All aims to provide comprehensive, affordable, and accessible care by expanding coverage to undocumented adults whose incomes are at or below 138% of the federal poverty level. If coverage was expanded to include adults regardless of immigration status, it is estimated that 25,000 older adults (65+) would qualify for full scope Medi-Cal. This report focuses on Latinxs who represent approximately 70% of the undocumented population.

As undocumented Latinxs elders age, they will be subjected to the same illnesses that afflict other senior citizens, often among the most expensive to treat: chronic diseases, cognitive disorders, and physical injuries. Diabetes, tuberculosis, and kidney failure are the most common illnesses among the older undocumented community. While undocumented older adults may experience high health needs as they age, their precarious status and other barriers precludes them from accessing care.

The study, UndocuElders in the IE, aimed to shed light on the experiences of undocumented older adults' health status and process of accessing care. In-depth semi-structured interviews were used to facilitate dialogue with undocumented older adults (N=30) ages 55-63 (M=61.67, SD=5.50). Most of the participants were Mexican (n=26, 87%) and had lived in the U.S. on average 21 years (SD=8.78).

## FINDINGS

- Participants were classified into a five-group typology that captures the intersection of perceived health status/need and access to health care; (1) High need, with access to care; (2) High need, with ambiguous access; (3) Undiagnosed need, with no access; (4) Perceived healthy status, with no access; (5) Healthy status, with access to care.
- Older adults who reported high health needs experienced a range of chronic and degenerative health conditions.
- Access to health care equated paying out-of-pocket for care. Participants pay between \$100-500/visit (i.e., consultation, laboratory bloodwork, and medications).
- High cost for care raises two critical issues – (1) cost is a barrier to accessing routine, preventative, and needed care; and (2) for those with chronic conditions, paying for care out of pocket is unsustainable as older adults age (e.g., reach a time when they are no longer able to work and/or expend their savings).
- Limited access to care leads to several detrimental consequences such as debilitated health, emotional burden, and economic insecurity.

## CONCLUSION

Findings from this qualitative study indicate that undocumented older adults experience health needs that require medical attention; many have minimal to no access to health care services or pay for services out of pocket, which is not sustainable overtime. While the state of California has been at the forefront of implementing policies that support immigrant integration, including health for all children, undocumented older adults remain without access to health care. Akin to children, older undocumented adults are a vulnerable segment of the population who need to be supported and cared for.

## ACCESS TO HEALTHCARE IN CALIFORNIA

In 2016, the state of California took a critical step towards reducing the health coverage gaps for undocumented Californians by expanding Medi-Cal eligibility to all low-income children using state funds.<sup>i</sup> Health for All aims to provide comprehensive, affordable, and accessible care by expanding coverage to undocumented adults whose incomes are at or below 138% of the federal poverty level.

<sup>ii</sup> If coverage was expanded to include adults regardless of immigration status, it is estimated that 1.15 million low income undocumented adults would qualify for full scope Medi-Cal; older undocumented adults (65+) make up 2% (or 25,000) of those who would be newly eligible for Medi-Cal.<sup>iii</sup>

## OLDER IMMIGRANTS AND HEALTH

Older immigrant adults are a vulnerable population. Approximately 16% of older adult immigrants live below the poverty line, 40% are members of low income families, and they tend to have less than a high school education and limited English proficiency.<sup>iv</sup> Immigrants tend to be healthier than their native counterparts upon arrival but lose that health advantage over time. As they age, they tend to develop chronic diseases, cognitive disorders, and physical injuries. Older undocumented adults face severe barriers to obtaining healthcare. Older undocumented adults do not qualify for Medicaid or Social Security benefits even though many pay taxes.<sup>v</sup> In general they are unable to afford private insurance,<sup>vi</sup> thus many rely on emergency rooms or community health centers for healthcare,<sup>vii</sup> which is only a temporary solution and drives up overall healthcare costs. Research on the health needs of older undocumented adults is scarce.

**UNDOCUELDERS IN THE I.E.** is a community based participatory study that sheds light on the health needs of undocumented older adults (55 years and older). A community advisory board (CAB) helped drive this study by identifying the research focus and study design. The CAB is composed of immigration and health advocates. In-depth semi-structured interviews were completed to examine undocumented older adults' perceptions on their health status and experiences accessing care. The sample is composed of 30 undocumented older adults who were on average 62 years old (SD=5.5).

Participants were primarily from Mexico (87%) and on average had resided in the US for 21 years (SD = 8.78, Range 1-36). The participants varied in their English speaking ability: 53% (n=16) reported only speaking Spanish, 40% (n=12) reported speaking some or very little English, and 7% (n=2) reported speaking English very well. Most participants reported yearly incomes below \$20,000.

## PROFILE

### LA SEÑORA ESPERANZA

El temor de tener que pagar

(I fear the expense)

La señora Esperanza is sixty-five years old. She resides in San Bernardino County and has lived in the U.S. since 2003. She rated her health as generally good; however, she experiences pain that materializes at the end of her workday when she is no longer physically active. She utilizes herbal teas to mitigate her pain. One day she noticed that her eye was red, and she attributed this to the dry air. The following day, she awoke and saw that her eye had become redder to the point of bleeding. It was not until her condition had worsened and with persuasion from her daughter that she sought help. Fortunately, she was able to receive treatment for her eye at a clinic in Fontana, where they sent her to the emergency room for additional exams and had the good fortune to be able to use emergency Medi-Cal to cover the cost. La señora Esperanza was then referred to a cardiologist because the ER doctors found that she had heart rhythm irregularities (arrhythmias). When asked if she planned to follow up on this referral any time soon, la señora Esperanza said no because she does not feel ill but also indicated the cost deters her from seeing a cardiologist, which is not covered by her emergency Medi-Cal. It has now been 1.5 years since the referral and she has not been to the doctor at all. In order to monitor her own health, she regularly checks her blood pressure and blood sugar levels at home. La señora Esperanza stated that she did not plan to see a doctor any time soon.

## THE INTERSECTION OF HEALTH AND ACCESS

Older adults were classified into one of five groups that capture the intersection of perceived health status and access to healthcare (see Figure 1). The five categories include (1) Undiagnosed need for healthcare, with no access; (2) Perceived healthy status, with no access; (3) High need for healthcare, with access to care; (4) High need for healthcare, with ambiguous access; (5) Healthy status, with access to care. For most participants access to care meant they paid out of pocket for services. At each level, participants experienced different risk based on their health needs and the barriers to care they face. Older adults describe steps they take to safeguard their health in the absence of healthcare.

### LIMITED ACCESS TO CARE

Several participants have limited access to healthcare or lack any access to care. Among the participants that reported limited access to healthcare, some perceived themselves as healthy while others suspected that they need medical attention. For the category “undiagnosed need for healthcare,” a 56-year-old participant shared that if he was able to visit the doctor, he anticipated he would be diagnosed with a medical condition. He experienced severe joint pain and shared, “Sometimes I feel faint; well I think I may have high cholesterol levels.” [What prevents you from seeking care?]

“There isn’t enough money, that’s the problem.” On the other hand, participants may perceive their health as “good or excellent” but often they have not seen a doctor in multiple years (2-5 years) due to financial barriers. One 62-year-old participant shared, “In the 20 years that I have been here, I have only been to the doctor 3 or 4 times...I try to take care of myself so that I don’t have to go to the doctor because it can be \$300-500 for a visit.” Similarly, many undocumented older adults reported forgoing regular checkups for years.

### AMBIGUOUS ACCESS

The participants who reported high need with ambiguous access are able to obtain care through emergency Medi-Cal, or Medically Indigent Services Program (MISP). Participants’ access is ambiguous as they are unsure how long they will have access to services given that they are undocumented and policies constantly change. Participants stated that without emergency Medi-Cal they would not be able to access care due to the cost.

“IN THE 20 YEARS THAT I HAVE BEEN HERE, I HAVE ONLY BEEN TO THE DOCTOR 3 OR 4 TIMES...I TRY TO TAKE CARE OF MYSELF SO THAT I DON’T HAVE TO GO TO THE DOCTOR...”

Figure 1. Perceived health status and access to care among undocumented older adults

<p>Undiagnosed need for health care, no access to care</p>	<ul style="list-style-type: none"> <li>• <i>Undiagnosed need for health care</i> is illustrated through signs or indicators that individuals may have a health condition that needs attention but has not been diagnosed by a medical doctor. Symptoms include dizziness, headaches, or body aches.</li> <li>• <i>Unable to access care</i> due to cost.</li> </ul>
<p>Perceived healthy status, limited/no access to care</p>	<ul style="list-style-type: none"> <li>• <i>Perceived healthy status</i>. Individuals report “I feel fine” or “I rarely get ill.”</li> <li>• <i>Limited/No access to care</i> – There is no recollection of last doctor’s visit or last health check was 2-5 year ago.</li> <li>• Health services are only sought out when necessary (i.e., medical crisis).</li> </ul>
<p>High need for health care, access to care</p>	<ul style="list-style-type: none"> <li>• <i>High need for health care</i> due to chronic conditions such as diabetes, high blood pressure or cholesterol levels; heart conditions, arthritis, and other ailments.</li> <li>• <i>Access to care</i> through community health clinics by paying out-of-pocket for services.</li> <li>• Cost is a major concern, regular visits to the doctor range between \$150-500, depending on their health status. Additional lab work, biopsies, and ultrasound may be needed which can range from \$100-250 per procedure.</li> </ul>
<p>High need for care, ambiguous access</p>	<ul style="list-style-type: none"> <li>• <i>High need for health care</i> due to chronic conditions; complications related to diabetes such as loss of eyesight and renal failure (i.e., need dialysis).</li> <li>• <i>Access to care</i> through emergency Medi-Cal and Medically Indigent Services Program.</li> <li>• <i>Access to care</i> is uncertain due to factors such as public charge. Participants fear losing access as it would be difficult for them to pay for needed health care.</li> </ul>
<p>Healthy status, access to care</p>	<ul style="list-style-type: none"> <li>• <i>Healthy status</i> based on regular visits to the doctor.</li> <li>• <i>Access to care</i> through medical clinics, participate in regular check ups including lab work.</li> <li>• Cost is not perceived as a barrier, can pay out-of-pocket for care.</li> </ul>

## HIGH HEALTH NEEDS

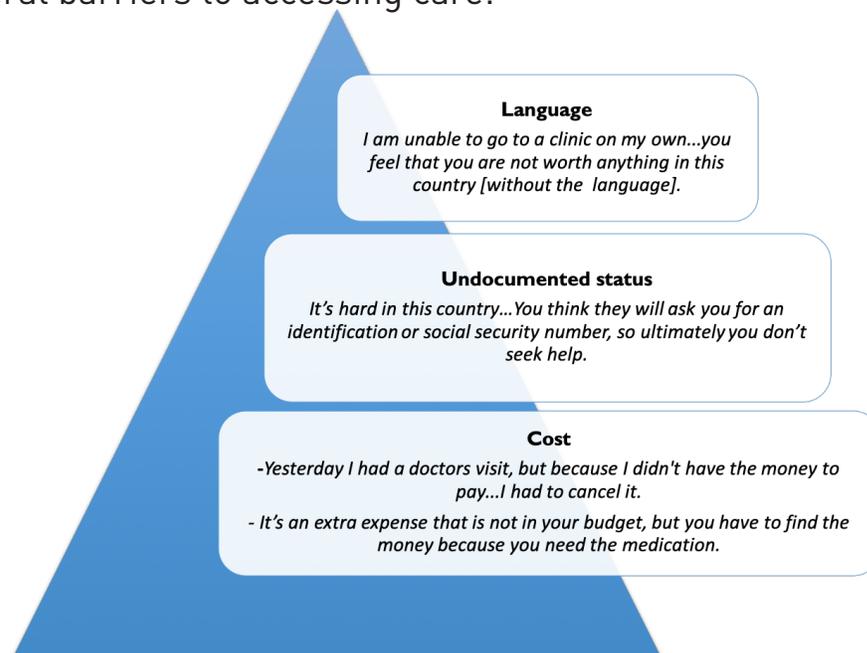
Older adults who reported high health needs experience a range of chronic and degenerative health conditions such as liver failure, high blood pressure, diabetes, and arthritis. These participants also reported delaying needed surgeries (e.g., cataracts, knee replacements, hand muscle repair). Older adults with high health needs typically report accessing care through community health clinics and paying out of pocket for care. Many participants require daily medications. A visit to the doctor, lab work, plus medications could range from \$100-\$500 per visit every 2-3 months. Participants with more advanced health conditions often need additional lab work, biopsies, and ultrasounds – one participant said that in six months she could spend up to \$1000 out-of-pocket.

## HEALTHY STATUS WITH ACCESS

A few participants reported their health status as healthy and had access to care. These participants were able to access care by paying out of pocket; they reported going for regular checkups every 6 months or yearly (depending on what their doctor recommended). These participants were grateful for their health and ability to pay for healthcare.

## BARRIERS TO ACCESSING HEALTHCARE

Older adults report several barriers to accessing care:



## LACK OF ACCESS TO HEALTHCARE AND THE TOLL ON OVERALL WELL-BEING

The lack of access to healthcare adversely affects the overall health of older adults, leads to additional stressors, and takes an emotional and financial toll on their family.

## SELF-CARE

Participants engage in a number of strategies to safeguard their health in the absence of healthcare. Several participants changed their diets, avoid drinking and smoking, and most take home remedies to prevent illness or care for their health. A 56-year-old participant who rated his health as poor, due to frequent dizzy spells, stated, “[I don’t] drink or smoke, and I eat fairly healthy; no red meat, maybe just once a week.” Another participant who had experienced joint pain said, “[I haven’t felt joint pain anymore] because I changed my diet...for almost two years I only ate vegetables...[now] I try to balance [my diet more] but still watch what I eat. But, I should go to the doctor to get a checkup.”

Some older adults reported self-medicating. For instance, a 58-year-old participant shared that her family members bring her medications from Mexico for her high blood pressure.

*When someone comes [from Mexico]...they bring my medication for six or five months. I don't buy medications here. Once you have high blood pressure, they say it's for life...Every night I check my blood pressure before I go to sleep...I have a little machine...If for some reason it's high I don't go to sleep until I control it. If it's high, I drink water, water, and more water and then to the restroom [she laughs]. That's how I learned to control my high blood pressure.*

## PROFILE

## DOÑA FLOR

The following participant shared how the high costs for surgery and rehabilitation as well as possible consequences for her family preclude her from seeking required knee surgery.

Doña Flor, who is 67-years-old, rated her health as fair. When she was asked why, she responded "...because I can still breathe." She went on to say, "I have an illness named osteoarthritis that is a degenerative disease." She experiences a lot of pain: "I take pills today and the next morning I wake up with the same pain, and I have to take the pills again and I would like to not have to depend on pain pills."

She continued to say, "I'm overweight so my knees are injured...I can't kneel anymore, or bend my knees...it's terrible." She has delayed required knee surgery because of the high costs. "The doctor told me that at a minimum the surgery for my knees would be \$3,000 plus rehabilitation which is indispensable. The rehabilitation...for each session...I can't recall how much it would be [but it was a lot]. I inquired whether I could access support such as Medi-Cal. But I worry because I wouldn't want to put [my family] in danger by asking for help [or using Medi-Cal]." Referring to her daughter and grandson she states, "They are the ones I care about because they want to be here in [the US]."

**RISK TO HEALTH.** For many older adults their health is placed at greater risk as they do not access prevention services, receive regular checkups, they may delay accessing care or needed treatment, and ultimately their health is debilitated (e.g., permanent loss of eyesight). The following participant, a 56-year-old male, describes what he envisions with a health plan is access to preventative care.

*"I think that to work here in this country goes hand in hand with healthcare. At a minimum, access to prevent an illness from getting worse. For instance, when you have a car you know that you have to maintain it - change the oil, an [engine] tune-up, so that your car doesn't experience a bigger issue or complete breakdown. For me access to healthcare to prevent a major illness is the best option. [As the sole provider for my family, preventing a major illness is critical] because if you get ill, you won't be able to work and everything falls apart without an income"*

### ...OFTEN THEIR ACCESS TO CARE WAS DELAYED, EXACERBATING MEDICAL NEEDS.

If undocumented older adults are unable to afford ambulatory care (e.g., visit to a doctor), delaying such services can exacerbate their medical needs. Several participants shared delaying surgeries (e.g., cataracts, knee replacements, hand muscle repair) due to high costs. For these participants, pain limited their mobility; for example, one participant shared not being able to kneel anymore, while another said that he was unable to close his hand into a fist. One of the more severe cases involved a woman who was unable to access healthcare and subsequently lost her vision in one eye.

### ADDITIONAL STRESSORS

Participants experience additional stressors beyond the impact on their health. There is an emotional burden placed on individuals when they are unable to pay for services or access the care they need. They constantly worry. Some participants report symptoms of depression (such as constant crying) and suicide ideation. There is loss of independence for several participants whose health conditions preclude them from working. The high cost of healthcare increases the economic insecurity in their households, with some households having to make the difficult decision of only securing the healthcare of one person and forgoing care for the other. The following quote illustrates the intersection of multiple stressors experienced by a 61-year-old adult. He struggles with diabetes, high blood pressure, and diminishing eye sight. He is also on dialysis. He is in a state of emotional distress as he worries about his ability to pay for day-to-day expenses after losing his job and his employer sponsored health insurance.

*Sometimes you don't feel well and you get desperate...I'm losing my eyesight in one of my eyes and I get depressed. I don't feel well and I don't have a job and I don't have money and [I have to]... pay rent, [for] food...I'm getting some help from [my co-workers]... they are helping me but it's not the same....my head will hurt...and it's hard for me to feel better...There have been times that I think about killing myself... la vida es triste porque en verdad...yo nunca habia sufrido como ahorita [Life is sad because in reality...I had never suffered the way I am now].*

## TOLL ON FAMILY

Participants fear how their health status may impact their families, emotionally and economically. Older adults may rely on their savings or family members to pay for care. One participant stated that he feared they would lose their house (which they paid for in cash). Another participant who lost her eyesight shared that her experience took an emotional toll on her and her family as they all felt helpless in their inability to raise the funds needed to get the surgery she required.

## CONCLUSION AND IMPLICATIONS

Findings from this qualitative study indicate that undocumented older adults experience health needs that require medical attention; many have minimal to no access to healthcare services or pay for services out of pocket, which is not sustainable over a long period of time. While the state of California has been at the forefront of implementing policies that support immigrant integration, including health for all children, undocumented older adults remain without access to healthcare. Akin to children, older undocumented adults are a vulnerable segment of the population who need to be supported and cared for.

- The urgent need for care was prevalent among older adults. Paying out of pocket for care is not sustainable in the long term and as their health deteriorates.
- Providing access to healthcare for undocumented older adults will eliminate or limit delays in seeking care, improve access to preventative care, and improve cost effectiveness by eliminating an overreliance on ER care as well as the long-term costs due to going without needed healthcare.
- Prevention programs for older adults can lead to significant cost savings – ranging from \$713-\$876 across various types of prevention programs.<sup>viii ix x</sup>
- Community organizations need to forge ties with older undocumented adults. Often this vulnerable population is not connected to support services in their community.

## ENDNOTES

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