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Listening to the Voices of Latinos in Omaha: Their Experiences and Ideas for Improving Access to Health Care

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The Office of Latino/Latin American Studies (OLLAS) at the University of Nebraska at Omaha (UNO) is a leading center in the region focusing on research, teaching, and engagement with the Latino population in the United States and throughout the Americas. This report is intended to generate policy discussions and actions that advance the incorporation of Latinos in Nebraska and the nation at large. For more information, visit: ollas.unomaha.edu

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INTRODUCTION

Latinos face a number of challenges in gaining access to quality health care. Among those challenges are the immigration statuses of adults and children, the cost of health care even with insurance coverage, the lack of health insurance, the limited availability of providers who are bilingual and bicultural, and difficulties adjusting to the health care system.

These challenges accumulate and intertwine with each other. Latino immigrants often need Spanish language interpreters to communicate their symptoms and to understand their diagnosis. It may be difficult to find a doctor or other provider who is not only bilingual but who also understands the variety of different Latino cultures. Immigration status affects where individuals can go for health care and if they have to pay out-of-pocket. Health insurance, including premiums, deductibles and co-payments are expensive, even on the Patient Protection and Affordable Care Act (ACA or "Obamacare") insurance exchanges. Community Health Centers are often the only place that serve the health care needs of most Latinos, especially those who are uninsured.

Other challenges can arise when families and their children are of mixed immigration status: those children who are born in the U.S. are eligible for Medicaid, and they can receive treatment at university medical centers and children's hospitals. Their brothers and sisters who are not U.S. citizens are excluded from Medicaid and coverage under ACA. If the parents are undocumented usually their only option is to pay out-of-pocket for themselves and their foreign-born children and to go to a Community Health Center for their health care needs.

ABOUT THE STUDY

The purpose of this study was to listen to the voices of Latino residents of the Omaha community who volunteered to share with us their experiences in accessing and receiving health care. A grant from the University of Nebraska at Omaha (UNO) College of Public Affairs and Community Service Dean's Office made this study possible. Dr. Carl Ameringer and Dr. Christine Reed, faculty members from the School of Public Administration (SPA), as well as project staff members, conducted four focus groups in South Omaha during May of 2015*. Dr. Christine Reed from SPA worked in collaboration with UNO's Office of Latino/Latin American Studies (OLLAS) during the summer of 2016 to develop this report.

The strength of focus groups, compared to surveys or interviews, is that participants engage in open-ended discussions, responding to broad questions from the facilitator and interacting with one another to share experiences and generate new ideas. Volunteers heard about the study from the local radio and from bilingual flyers left in various locations. They were all 18 years of age or older, lived in South Omaha as well as surrounding areas, and had experiences with the health care system that they were willing to share with us. We relied on them to identify important areas of concern, as well as ideas about improving the health care system, rather than use a panel of professionals to identify important issues.

The results of those focus groups are summarized in this report. The participants offered powerful first-hand information about issues that might have escaped the attention of providers and community partners. Although they were not a representative sample of the South Omaha community or its surrounding areas, their experiences provide a unique window into the strengths and weaknesses of health care delivery as experienced by Latino residents.

The facilitator of the focus group sessions, Mr. Alberto Cervantes, conducted all of the conversations in Spanish and asked at the beginning

* Dr Carl Ameringer served as the Principal Investigator during the study. Dr. Christine Reed was the Co-PI.

of each session for permission to record the focus group conversations. A staff member from OLLAS transcribed and translated the recorded sessions.

All of the sessions were confidential. The participants withheld their names. Individual participants could also choose which questions to answer.

The number of participants and locations of the four focus groups are listed in Table 1.

Table 1: Location and Participants

Focus Group	Location	Participants
1	South Omaha Public Library	16
2	Stephen Center	7
3	South Omaha Public Library	12
4	South Omaha Public Library	1
Total		36

The age range of the participants is reported in Table 2.

Table 2: Age Reported by Participants

Age	Frequency	Percent
18-29	5	11.1%
30-39	7	19.4%
40-49	11	36.1%
50-59	6	16.7%
Over 60	5	13.9%
No Answer	2	2.8%
Total	36	100%

At the beginning of each session, the facilitator asked about the participants' country of origin (See Table 3). The majority of them were Mexican immigrants (86.1%) while the rest were either Cuban immigrants or U.S. born.

Table 3: Country of Origin Reported by Participants

Country of Origin	Frequency	Percent
Mexico	31	86.1%
U.S.	1	2.8%
Cuba	4	11.1%
No Answer	–	–
Total	36	100%

Less than half of the participants reported that they had health insurance, whether that included private or public (Medicaid or Medicare) plans, as shown in Table 4.

Table 4: Insurance Coverage Reported by Participants

Insurance	Frequency	Percent
Yes	16	44.4%
No	5	13.9%
No Answer	15	41.7%
Total	36	100%

A little more than half of the participants said that they went to OneWorld Community Health Centers (OneWorld) for basic adult health care (See Table 5). As we suggested in the introduction, when children are born in the U.S. they are eligible for Medicaid. Participants told us that they take their Medicaid-eligible children to University of Nebraska Medical Center (UNMC), Boystown or Children's Hospital; while they take their undocumented children to the place where they go for adult care, such as OneWorld.

Table 5: Source of Adult Primary Care Reported by Participants

Adult Primary Care	Frequency	Percent
OneWorld Community Health Center	20	55.5%
Alegent Creighton Clinic	3	8.3%
UNMC	1	2.8%
SOMA	1	2.8%
ER	1	2.8%
Home Remedies	1	2.8%
Does Not Specify	6	16.7%
No Answer	3	8.3%
Total	**36**	**100%**

THE MAJOR ISSUES RAISED BY PARTICIPANTS

It is important to emphasize three points. First, each focus group did not necessarily raise the same issues. Second, additional issues might have emerged from additional focus groups. Third, we identified six separate issues, but they tended to intertwine with each other, because they were interrelated. Each of the following sections begins with an overview of the issue, followed by a summary of the discussions.

PREVENTIVE HEALTH CARE

The term "preventive care" covers a range of health care services, from childhood vaccinations and annual check-ups to management of chronic illnesses, such as diabetes and high blood pressure. In the U.S., there is a growing emphasis on preventive care, however this is still a slow trend. In addition, the approach to medical care, whether preventive or otherwise, differs across Latin American countries and there are cultural differences in how individuals from those countries determine when medical care is needed. These cultural differences may affect how Latinos decide when to access health care in the U.S.

Many participants said that they wait until they have symptoms before seeing a doctor; but their reasons also include barriers built into the U.S. health care system itself such as cost, lack of health insurance and being afraid of language barriers, paperwork and immigration status.

Accessing preventive health care depends in part on having a regular doctor, defined by the focus group facilitator as "a person you see when you have certain health conditions or [go to] just [for] a complete physical exam." In one focus group, half of the participants reported having a regular doctor. In all four focus groups those who had regular doctors saw them for chronic health conditions, such as high cholesterol, asthma, chronic pain, diabetes and depression in addition to their routine check-ups. Some chose their regular doctor for non-medical reasons, especially proximity to their homes and/or because their doctors were Spanish/English bilingual.

Those who had a regular doctor went to OneWorld, UNMC or Creighton. Those without a regular doctor chose OneWorld, UNMC or a hospital emergency room (ER), and their reasons included emergencies as well as regular check-ups, women's health and cancer screenings. Most of those who did not have a regular doctor said that they lacked health insurance and that the cost of an office visit was therefore too high. Even those eligible for insurance stated that the co-pays for office visits were too costly. One participant explained, "They don't go because if you don't have insurance you're thinking about how it's going to be another bill to pay - - you won't be able to pay it. And if there's no necessity, an emergency, well it is better not to go."

Even though some wait to seek out health care, they may find that once they get to an ER, they may be turned away unless their condition is deemed to be an emergency by a physician. One participant described this experience: "I went to the emergency room two months ago, and they didn't want to do anything. I had a pain. I have a problem with my

vertebra. Nothing: They told me, 'Only if you come in and can't walk at all we can see you.' That's the only thing they told me, 'We can't.'"

Another participant when explaining why some Latinos may wait to seek out care put it this way: "They only go when it's necessary, not for routine stuff like if they have a cough better to buy medicine. It's better than going to the doctor for stuff like that." As explained earlier, the reasons why Latinos may experience difficulty in accessing a regular doctor "stack up" one on top of the other. Participants reported that Latinos do not go because offices may lack Spanish interpreters, or there may be a limited number of providers who are nearby to where they live. They also discussed how important it is to feel welcomed, understood, and respected by providers and staff.

Barriers to accessing preventive care are complex. The next sections examine the interrelated issues of immigration status, insurance coverage, language and bicultural interpreters with access to children's health, dental and occupational health. Participants often described their experiences by referring to several of these issues at once in response to questions from the facilitator. Still, it is helpful to break down those discussions by highlighting one major issue at a time. One of the greatest barriers to accessing affordable health care is immigration status, because it determines who is eligible for Medicaid or Medicare as well as who can purchase private policies on the ACA health insurance exchanges.

IMMIGRATION STATUS

Immigration status can be a significant barrier to accessing health care. According to his presentation "The Intersection of U.S. Immigration Law and Healthcare: A case for the creation of immigrant-focused medical/legal partnerships," Charles "Shane" Ellison, Legal Director and Deputy Executive Director of Justice for Our Neighbors-Nebraska (2016), for all immigrants who have resided in the U.S. for less than five years, the rate of those without health insurance is 73.2% while 71% of undocumented adults lack any health insurance. There is a five year waiting period before immigrants qualify for federal benefits such as Medicaid, and those benefits are completely unavailable to those who are undocumented. ACA excludes undocumented immigrants from the health insurance market exchanges as well. Finally, those under the Deferred Action for Childhood Arrivals (DACA) immigration policy are excluded from Medicaid and Medicaid's Children's Health Insurance Program (CHIP) as well as the ACA exchanges and any subsidies that would lower the cost of insurance premiums.

In Nebraska, according to Ellison, there were 123,000 immigrants in the year 2013. About 45% were undocumented, and an estimated 71% were uninsured. The situation is better for children born in the U.S., because they are citizens. 85% of these children in Nebraska and with immigrant parents are eligible for Medicaid. In addition, according to the National Immigration Law Center (2016), the State of Nebraska has added the option, now available through the federal Medicaid program, to waive the five year waiting period for lawfully residing children and pregnant women, also making prenatal care available for undocumented women. Community Health Centers, such as OneWorld, are often the only source of health care for undocumented immigrants because they accept patients without insurance on a sliding fee basis, but individuals and families have to contribute to the cost of their health care.

One of the focus group participants made the ironic observation that the only right he (and others who are undocumented) have is not being obligated to purchase insurance. Otherwise they would face a tax penalty. He went on to explain "For us, well the ones who don't have documents, it's more, a bit more difficult. We're not left with other options." Another participant shared frustration with

insurance companies that exclude family members from coverage, even if the head of the household is documented and insured because they themselves are not documented.

Finally, one participant shared her experience in applying for financial assistance. "But for a Hispanic person like myself, to apply for financial assistance because I don't have insurance I have to fill out a ton of papers, papers that perhaps I don't have an understanding of filling out so many requirements, you understand me? I need to ask for help filling out all that paperwork and we, sincerely, as Hispanics sometimes prefer to avoid all of this. At times we have no other choice we do it." Her shared experience echoed what other participants expressed about why they often wait until they are very sick before they seek out health care: those who lack insurance, whether or not they are undocumented, have few options when choosing regular doctors.

CHILDREN'S HEALTH CARE

According to Athena Ramos (2013) and her co-authors in their report "Health Profile of Nebraska's Latino Population," 13.6% of the Latino population in Nebraska is younger than five years old, and 27.8% are between the ages of 5 and 17 years. Slightly more than 40% of all Latinos in Nebraska are children and youth. As discussed earlier, 85% of children born to immigrant parents are U.S. citizens, and those children qualify for Medicaid, but some Medicaid eligible children remain uninsured according to Ellison's presentation. The main reason is that "while U.S. citizen children of undocumented immigrants qualify for benefits, they face barriers to health care because of the fear that the undocumented family might be reported to immigration authorities as a result of the child's participation" (Ellison 2016, p.16).

Some families have children with a mixed immigration status. Some are eligible for Medicaid and others are undocumented and therefore not eligible. Those who are legally protected by President Obama's Executive Order creating DACA are excluded from both Medicaid and access to health insurance through the ACA insurance exchanges. Although these are a relatively small percent of the total population of children and youth in the U.S., they must depend on Community Health Centers along with their undocumented parents for their health care. Families with children of mixed immigration status may choose a university medical center or children's hospital when Medicaid will reimburse them, and then choose a Community Health Center provider for themselves and their uninsured children.

Focus group participants who had children with mixed immigration status were clear in discussing that they took their children to UNMC or Children's Hospital if Medicaid would cover their medical expenses. They wanted what they believed was best for their children, even if it meant traveling a greater distance or dealing with Spanish/English interpreters. Their comfort level with OneWorld was less important to them than getting their children the best possible medical care. One participant had five children, three of whom were protected by DACA. For those three children he had no options in choosing a provider and had to pay out-of-pocket. He therefore chose the least expensive provider. The other two children were covered by Medicaid through a contract with United Healthcare. These two children therefore had more options in choosing a provider and were provided financial assistance through the Medicaid program.

Another participant shared her experience having children with multiple immigration status. "But for example my son, the youngest, I took him to the emergency room in February. Medicaid sent me the bill of what they paid for and it was $1,700 for four hours in the emergency room. Can you imagine with only my husband working and if I have to pay for my oldest daughters a payment like this for

an emergency? I don't have it. I have to apply for reduced payments or to pay in payments no?" In her case Medicaid covered her son's ER visit, but if it had been one of her daughters without Medicaid she would have needed to apply for financial assistance. These stories from participants show how important it is for Latino parents to find what they believe is the best health care for their children, in spite of a complex system of public and private health insurance with different eligibility requirements.

Many participants shared that they postponed their own doctor visits for healthcare if they felt it was unnecessary or expensive. However, they felt strongly about finding a way to access and pay for doctor and hospital visits when their children's health was at stake. Their experiences help to shed light on the issue of medical homes for children, defined by the Maternal and Child Health Bureau (2015) as 1) having a personal doctor, 2) having a usual source for sick and well care, 3) receipt of family-centered care, 4) no problems getting needed referrals and 5) receipt of effective care coordination when needed. Hispanic children are less likely to have a medical home than are non-Hispanic whites: 37.2% versus 65.7%. Children with private insurance are also more likely than children with public insurance or no insurance to have a medical home: 64% versus 43.9% and 27.8% respectively (Maternal and Child Health Bureau, 2015).

In the future, Community Health Centers like OneWorld will be able to build on reforms in the healthcare system in order to work toward a medical home model for Latino children who go there for health care. The Medicaid program has tended to focus their efforts to create medical homes for children with special health care needs, but as the statistics suggest there is still a need to channel those efforts to include comprehensive child care. Considering that Latino children and youth now make up about 40% of the Latino population in Nebraska, and that a small but significant proportion of them are excluded from public and private insurance coverage, this issue is worthy of further study and action.

BILINGUAL AND BICULTURAL PROVIDERS AND INTERPRETERS

A recurring theme across all four focus groups was their experience in accessing and receiving health care from providers who were bilingual and bicultural. These participants considered it essential to receive care from doctors and staff that understood them and could communicate across cultures and language barriers. According to OLLAS (2015), "Latinos throughout the City: A Snapshot of Socio-Demographic Differences in Omaha, Nebraska," the Latino population is a very diverse community. They live in all parts of the city, however 56% of the Latino population live in South Omaha (South East zip codes.) Nearly half of those five years and older living in South Omaha reported speaking English "not well" or "not at all" compared to 37% in the city as a whole.

Most focus group participants expressed some unfamiliarity with the English language, especially when speaking, and emphasized that finding health care providers who were bilingual and bicultural was a deciding factor in seeking health care facilities like OneWorld. In fact, finding a provider who was bilingual often presented its own challenges: unless Spanish was the native language of the provider, there were significant barriers to communicating symptoms and understanding diagnoses and treatment plans. Most of the experiences with Spanish/English interpreters were negative, because the interpreters had some difficulty in translating medical terms or because patients were afraid that the interpreters were holding back from communicating what patients were really trying to say.

One participant expressed her reason for going to OneWorld: it was accessible to her. She was comfortable going there because everyone spoke Spanish. She had the option of getting care in other places, but she chose OneWorld because she did not have to ask for an interpreter. "I do, my children, the oldest ones they're always telling me, they say 'Ma, why do you go to...OneWorld? Why don't you look for a hospital and go to the hospital to look for a specialist there for that? For this? Why do you always go there?' But the reason for why I go to, I don't go to a hospital is for the language. Like the man said, it's more practical here, it's more comfortable because they give everything in Spanish here. In a hospital, we have to bring an interpreter or we have to find an interpreter." Many hospitals and clinics provide interpreting services when asked for them. Aside from providing interpreters to patients, there may also be a need to educate patients on the services that are made available to them.

Many participants thought that the Latino community of Omaha is in need of more bilingual health care facilities. One participant stated, "Yes, I think so as well. I think there should be more places and above all that, just as the Latino community is growing, perhaps bilingual, would be better for those people. Because, well sometimes I do think that people feel fear, I went through that and, well, it's like you have fear of going and not being understood. I've also had to go and there have been way too many patients as well (at OneWorld.) You have to be there four, five, seven hours in the clinic. So all of that yeah is the, I wanted there to be possibly more places as well."

Some participants also found it difficult to communicate their symptoms even if they are familiar with the English language. One participant mentioned how speaking in a medical setting was very different than a school setting for her. "I mean it's very different when we try to speak, to communicate in, even at school, going with a doctor is, because it's now internal problems, so it's more difficult. I have had problems in communicating as well".

Other participants shared their frustration with poor interpreting services. "And you don't know if they're transmitting [that message] exactly what, the sense of it the pain what you're enduring. How to tell that doctor, no." Many thought that interpreters did a poor job telling the doctor exactly what they were expressing at the time. One participant said "Translation services exist but there is not one translator that has the courage to tell the doctor what you're saying, and I would like them to change that." As one participant also put it, "That's why they want that another person goes with them so that they can help them understand the interpreter." These difficulties occurred less often at OneWorld where providers and staff are bilingual, and more often at hospitals or at the offices of other health providers.

Participants made it clear that even though there are places outside of OneWorld where assistance is available for Spanish speaking patients, OneWorld has a number of different departments in one building, such as check-ups and eye care. That model is hard to find elsewhere. For those whose barriers get "stacked up" (language, transportation, immigration status and time constraints), having a one-stop health care facility for different health-related services is a model that they need and appreciate.

DENTAL HEALTH

Another issue raised by focus group participants was dental health. Dental health is an issue in the Omaha Latino community, especially for children. So called 'food deserts' – areas where it is hard to get affordable fresh food produce - can be a barrier to dental health, because processed food including fast food can cause tooth decay. Even those with insurance may find the co-pays for office visits unaffordable. Those without insurance can

find it impossible to pay for dental problems that require root canals or other expensive procedures. Some dental schools periodically offer free dental cleanings but this may not be a sufficient solution in addressing the needs of this community. One participant shared this experience, "I barely have any molars. I don't qualify for any insurance, the only thing I do is every time that I have a strong pain they take one (molar) away. I almost don't have (any molars) because it costs me more than $1,000 for a treatment. $3,000, $5,000 what do I prefer? Better for them to remove the molars and the pain goes away. We have to endure it."

OCCUPATIONAL HEALTH

Occupational safety and health was a topic raised in one of the focus groups, and there was an in-depth conversation about this topic. Latino immigrants who work in meat-packing, construction and hotel cleaning jobs are susceptible to repetitive work-related injuries or to repeated exposure to chemical solvents used to clean rooms. Even those who have insurance find that the co-pays for visits to physical therapists or chiropractors are unaffordable. If these injuries are left untreated they can lead to more serious chronic conditions, requiring orthopedic surgery or treatment for respiratory illnesses. In addition, undocumented immigrants may choose not to apply for worker's comprehensive insurance for fear of having to show proof of their legal status. This forces many undocumented immigrants to go untreated for their illnesses or injuries which can result in further health complications.

One participant explained how the fear of losing a job can keep people from seeking occupational health care, and how this could lead to chronic conditions that require more time and care. "They come here and they don't have any papers, they get illegitimate papers or what have you, but if they have some pain or they feel ill, they don't say anything because they could lose the job. And they keep adding on to that pain and that pain from four, five, six years turns into a thing called chronic pain that even St. Peter can't take away if he comes down."

A suggestion from the focus group was having a place where workers could receive an initial diagnosis at no cost where "...they can go so that they can know what they have because many who go where I am, they don't even know what they have and neither do I." An occupational health center where providers assess work-related injuries might prevent workers from trying to second-guess what their diagnoses could be by talking to friends and co-workers, or putting off seeking professional help. If workers are postponing health care because they are afraid of missing work and possibly losing their jobs, then this fear adds to the stress of finding affordable health care, such as physical therapy. Even the top-tier private insurance plans cap the number of visits, because they cover only accidents or other acute situations. Chronic work-related conditions require a different model of health care.

CONCLUSION

This report reflects the voices of Latino immigrants from the South Omaha and nearby communities as they have shared their experiences with the health care system. The purpose of the project was to listen to those voices and to what they identified as the most important issues, instead of asking health care providers or academic researchers to define the problems. The next step is for providers and community partners to listen to those voices and to develop workable solutions. Those solutions may require policy changes at the local, state and federal levels, but it is first necessary for all those who serve the health needs of the Latino community to come together and to address the issues identified in this report in a systemic and holistic fashion.

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