



Healthcare Reform in Latino Rhode Island: Perspectives of Spanish speakers and Insurance Navigators

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Abstract

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Keywords

Healthcare Reform; Insurance Expansion; Hispanic/Latino Health; Health Disparities

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ABSTRACT

Latinos have the highest uninsurance rates of any ethnic or racial group in the US despite recent health insurance expansion reform. In addition to immigration and language barriers, health literacy and attitudes may impact coverage disparities. Focus groups with Spanish-speaking community members and semi-structured interviews with health insurance navigators were conducted to explore knowledge, awareness, and attitudes towards healthcare reform among Latinos in Rhode Island. Sessions were audio recorded, transcribed, and analyzed employing standard qualitative methods. Thirty-two focus group participants and six navigators were enrolled in the study. Spanish-speaking participants demonstrated limited knowledge of the cost implications of the Medicaid Expansion and of the role of health insurance exchanges. Common misconceptions included that insurance costs would increase regardless of income, that enrollment would compromise green card and citizenship applications, that documented non-permanent residents would be ineligible for subsidies, and that reform benefits would apply to undocumented workers. Our findings suggest that local initiatives and providers should target Latinos in a culturally sensitive manner to increase literacy regarding insurance eligibility, affordability, points of access as well as to address misconceptions related to insurance eligibility for documented immigrants.

Keywords: healthcare reform, insurance expansion, Latino health, health disparities

INTRODUCTION

Latinos have been the most likely of any racial or ethnic group to lack health insurance in the United States in recent decades (National Center for Health Statistics, 2012). The passage of the Affordable Care Act (ACA), which enabled states to expand Medicaid and to create marketplaces that offer tax-credits to subsidize health insurance, improved health prospects for Latinos. Nonelderly adults with household incomes up to 138% of the federal poverty line (FPL) qualified for free health insurance, whereas those up to 400% of the FPL qualified for subsidies. National insurance rates for Latinos increased by 13% after the first enrollment period under the

ACA; nevertheless the group remained uninsured at more than twice the rate of the general population (Doty, Blumenthal, and Collins, 2014). After the second ACA enrollment period, more than 32 million nonelderly individuals nationwide were uninsured and over a third (34%) were Latinos (Artiga, Damico, and Garfield, 2015), who comprise 17.6% of the US population. Though Latinos were also less likely than non-Latinos (41% vs. 52%, respectively) to be eligible for insurance assistance under the ACA due to immigration status (Artiga et al., 2015), more factors must be examined to explain the degree of health insurance disparities affecting Latinos.

Health insurance expansion for many Latinos may entail two barriers to coverage: limited English proficiency and the new, complicated process of insurance enrollment. Language has been identified as a barrier to insurance expansion at both the state and national levels. Three years after the Massachusetts Health Connector inauguration in 2006, the coverage increase among Latinos doubled that of non-Latino whites; yet coverage remained higher for non-Latino whites (96%) than for Latinos (79%), and even more so than for Latinos with limited English proficiency (66%) (Maxwell, Cortés, Schneider, Graves, and Rosman, 2011). Nationally, primarily Spanish-speaking Latinos were one and half times more likely than English-dominant Latinos to stay uninsured after the first ACA enrollment period (Doty, Rasmussen, and Collins, 2014).

The new complexities posed by the ACA regarding insurance acquisition are evident in the benefits eligibility criteria and the new enrollment process. Eligibility criteria for ACA benefits for immigrants are intricate and can differ across states. For instance, states can decide whether lawfully present children or pregnant women are subjected to a five-year period of living in the US before qualifying for Medicaid (Stephens and Artiga, 2013). Moreover while insurance marketplaces were meant to simplify the process of acquiring insurance, they represent a new component in a healthcare system already difficult to navigate. After the first ACA enrollment period, only half of potentially eligible Latinos nationwide were aware of insurance marketplaces, compared with nearly three-quarters of non-Latino whites; and less than a third of potentially eligible Latinos had visited a marketplace, compared to nearly half of non-Latino whites (Doty, Rasmussen, and Collins, 2014).

While English proficiency may partly explain barriers to insurance expansion unrelated to immigration status, health literacy and attitudes must also be studied. The qualitative portion of a large Massachusetts study indicates that factors such as familiarity with the insurance mandate, perceptions of coverage affordability and enrollment complexity, along with cultural attitudes, may play an important role in coverage disparities (Zhu et al., 2010). Limited data exist across states on the role that attitudes and beliefs toward health insurance reform may play for Latinos, who represent a wide variety of cultures and national origins.

In Massachusetts, Latinos remained uninsured at more than twice the rate of the general state population one year after the first enrollment period through the Health Connector, which served as the model for nationwide health insurance marketplaces under the ACA (Nordahl, 2009). Despite a successful grant program for outreach and enrollment as well as initiatives from provider groups, ongoing assistance for reenrollment and navigation from local agencies was required in Massachusetts (Zhu et al., 2010). Health insurance navigators are trained and certified to educate and guide individuals through eligibility criteria, documentation requirements, coverage differences among plans, benefits application processes, and actual enrollment and reenrollment for insurance (Centers for Medicare and Medicaid Services, 2015). In Massachusetts, they proved effective in helping Spanish-speakers complete varied health-related tasks (Charlot et al., 2015; Congdon, H. B., Eldridge, B. H., and Truong, H.-A., 2013;

Lasser et al., 2011). By 2011 in Massachusetts, the rate of uninsured Latinos decreased from 21% in 2009 to 10% (Pew Research Center, 2011).

Latinos are Rhode Island's major minority group and comprise 14% of the population. Eighty percent of Rhode Island Latinos reported speaking a language other than English at home, 29% live in poverty, and nearly 40% report being foreign born – with Dominican Republic, Puerto Rico, and Guatemala being the most represented country/territory origins (U.S. Census Bureau, 2014). Prior to the institution of HealthSource RI, the state's health insurance marketplace, 41.2% of Latinos in Rhode Island were uninsured, compared with an uninsurance rate of 17.9% in the general state population (CDC BRFSS data, 2011-2013). After the first ACA enrollment period, the uninsured rate for Latinos dropped more than half (to 17.2%), but remained more than twice that of the state's general population (7.4%) (U.S. Census Bureau, 2014). For non-pregnant adults in Rhode Island, eligibility criteria for free Medicaid insurance include household income up to 138% of the FPL and citizenship or legal residence for more than 5 in the US. Since census data reports that around 86% of foreign-born Latinos have lived in the US since 2009, there is a need to examine barriers to insurance other than immigration status.

Health insurance expansion can improve health and socioeconomic factors for Latinos nationwide (Baicker et al., 2013; Sommers, Long, and Baicker, 2014). Rhode Island has been a leader in ACA implementation, obtaining federal grants and investing in awareness campaigns and navigation systems in similar proportions to states like New York, Colorado, and Oregon (Blumberg et al., 2014; Holahan, Rifkin, Lucia, and Keith, 2012). To achieve a greater understanding of health literacy and attitudes in the context of healthcare reform and to develop culturally aware interventions, we conducted qualitative research with major stakeholders in Latino enrollment: Spanish-speaking Latino adults and health insurance navigators.

METHODS

We conducted this qualitative study in two parts: focus groups with Latino adults before the first ACA enrollment period followed by individual in-person semi-structured interviews with health insurance navigators before the second ACA enrollment period.

Conceptual Framework and Instrument Development

We developed open-ended question guides based on recurring themes in relevant literature, professional experiences in clinical settings, and the Social Contextual Model of health behavioral change – a theoretical approach for intervention design that calls for inquiry into how social circumstances impact health behaviors (Sorensen et al., 2003). The question guides were developed in English first and then translated into Spanish by one bilingual individual. All co-authors (who are bilingual) then reviewed the translation, and discrepancies were discussed and modified until all co-authors were satisfied with the accuracy of each translated question. We conducted one pilot-test focus group that consisted of five Spanish-speaking Latinos, and two pilot-test interviews, one with a social worker and another with a health insurance navigator. Based on these pilots, we adapted the moderator guides by circulating them among all co-authors and meeting as a group to come to agreement about final inclusion, wording, and translation of questions.

Topics addressed by the focus group and interview guides included health insurance status, motivation to acquire health insurance, attitudes towards healthcare reform, knowledge of reform regulations and benefits, awareness of the insurance marketplace, barriers to insurance, perceived cost and quality changes associated with the ACA, and future recommendations for

outreach (see examples of questions in the supplemental pages section). The focus group and interview guides were designed to probe into how the main topics were influenced by income, immigration status, culture, language preference, transportation, education level, political views, religious views, and media preference for obtaining news information. We developed the focus group and interview guides to include all pertinent core questions related to our study topic. Given that core questions are naturally supplemented with follow-up questions and probes relevant to each evolving discussion, the exact number of questions in each interview and focus group varied. During implementation of the interviews and focus groups we remained alert to their length, and whether participants appeared to be uncomfortable or tiring from excessive length (Ulin, Robinson, and Tolley, 2005).

Data Collection

For this qualitative study, we first conducted five focus groups with Spanish-speaking Latino adults using a semi-structured question guide. Focus groups met between July and November 2013, months prior to the first ACA enrollment period. Next, we conducted six individual semi-structured interviews with navigators trained to enroll individuals for health insurance under the ACA. Interviews took place in October and November of 2014, immediately prior to the second enrollment period under the ACA.

Focus groups lasted between 1 and 1.5 hours and were held within the greater Providence area at Memorial Hospital of Rhode Island and two social service agencies. Individual interviews lasted between 20 to 40 minutes and were held at the navigators' offices. All focus groups and one of the individual interviews were conducted in Spanish, while the remaining interviews were conducted in English. Each focus group and interview was conducted by one research team member (HRB) fluent in Spanish and English, audio recorded, and professionally transcribed in the original language. The accuracy of the transcriptions was verified by reviewing transcripts against original recordings. The Memorial Hospital of Rhode Island Institutional Review Board approved the study and written consent was obtained before focus groups and interviews. Focus group participants received refreshments and a \$30 incentive for participation; navigators did not receive incentives.

Participants

Women and men aged 18–65 years were considered eligible for focus groups provided they could participate in Spanish. Focus group participants were recruited through flyers at local businesses and at community organizations offering ESL and GED courses within the greater Providence area. Interested individuals called our research phone line and spoke with the primary bilingual investigator who screened for eligibility. We used purposive, criterion-based sampling to recruit as heterogeneous a sample as possible within our eligibility criteria (Kuzel, 1999). As people responded to our community flyers and called our screening telephone line to register for participation, we kept track of personal characteristics and different Latino countries/territories of origin who live in RI in order to recruit a diverse sample of participants.

Navigators trained to enroll individuals for health insurance were considered eligible to participate in interviews. Interview participants were recruited via phone calls to their work sites, using HealthSource RI lists available online. The bilingual primary investigator spoke with potential participants and screened for eligibility.

Data Analysis

Focus group and interview data were analyzed in several stages. The moderator/interviewer reviewed notes written during or immediately following each group and interview to acquire further familiarity, begin to isolate initial data patterns, and to iteratively adjust the question guides. The moderator/interviewer then read and analyzed the transcripts to identify initial categories discussed (Emmerson, Fretz, and Shaw, 2011). Transcripts were continually analyzed by all co-authors individually and collectively utilizing “immersion–crystallization”, a qualitative analysis method comprising cycles of concentrated textual review of data, combined with reflection and insights, until final interpretation of the data becomes apparent (Borkan, 1999).

Over a series of meetings with all co-authors, we discussed our individual analyses, identified additional categories and themes arising in the data, and discussed potential interpretations. The final set of topical data analysis categories for focus group transcripts comprised *insurance status, attitudes toward insurance, knowledge of healthcare reform, awareness of insurance marketplace, attitudes toward reform, community knowledge needs, and misconceptions*. For navigator interviews, the final set of categories of data topics included *knowledge of healthcare reform, motivation to seek insurance, misconceptions, fears, knowledge gaps, barriers, and outreach recommendations*. For each identified category, the team identified illustrative comments made by participants. Discussions continued until consensus about final interpretation of the data was reached.

The team was comprised of different perspectives: two medical students, one medical anthropologist, and one practicing physician with graduate training in public health. Translation of transcript excerpts into English was undertaken in preparation for publication.

RESULTS

A total of 33 Spanish-speaking adults (21 female; 11 male) participated in 5 focus groups. All participants chose “Latino/Hispanic” for their ethnicity on the demographic survey. For race, the most frequent response (10 instances) was writing in “Hispanic” under “Other”. Except for one, all focus group participants were born outside of the continental US, primarily representing three countries/territories of origin: the Dominican Republic, Colombia, and Puerto Rico. Participants had lived in the US between 2 months and 30 years, with the average being 12 years for females and 11 years for males. Based on the Brief Acculturation Scale (Marin et al., 1987), participants displayed a moderate level of acculturation based on language preference with over half of participants speaking Spanish only at home (53.1%).

Over three-quarters of participants reported a household income less than \$25,000/year (77%) and more than half of focus group participants had health insurance coverage (56%). More details are provided in Table 1. Data on immigration status and household size was not gathered. However, based on length of residence in the US, household income, and insurance status, the majority of participants were likely to be eligible for tax-credits, if not free Medicaid insurance, under the ACA.

Semi-structured interviews were conducted with 6 participants. All navigators worked as navigators for HealthSource RI and thus were trained and certified in insurance enrollment under the ACA. Most navigators worked in urban settings within Rhode Island, except for one who worked in a suburban health center. All interviewed navigators were affiliated with primary care clinics.

Table 1: Demographics of Focus Group Participants

	Female (n=21)	Male (n=11)
Age—mean (SD)	43 (14)	41 (16)
Insured (%)	33	55
Country/Territory of Origin		
Dominican Republic (%)	33	46
Colombia (%)	38	27
Puerto Rico (%)	19	27
Other (%)	10	0
# Years in US—mean (SD)	12 (7.6)	11 (11.6)
Language Spoken at Home		
Spanish only	52	54.5
Spanish more than English (%)	29	45.5
Both Spanish and English equally (%)	10	0
English more than Spanish (%)	10	0
English only (%)	0	0
Brief Acculturation Scale*—mean (SD)	7 (3.3)	7 (1.9)
Level of Education		
< High school (%)	33	18
High school or GED (%)	24	18
>High school (%)	43	64
Yearly Household Income		
<\$25,000 (%)	71	73
\$25,000–49,999 (%)	10	9
>\$50,000 (%)	5	9

*See Marin et al., (1987)

Abbreviations: SD, standard deviation; US, United States; GED, general educational development

Focus Groups with Spanish-speaking Latinos

Participants uniformly ascribed high value to health insurance, identifying the impact it can have on diverse aspects of everyday life. Several uninsured participants reported not seeking medical care for acute concerns due to lack of health insurance:

“A lot of people want to go to the hospital but because they do not have health insurance, they decide not to go.”

When asked what health insurance means to them, participants often reported that having health insurance promotes use of preventive medical services and decreases medical visits due to late disease manifestations:

“Preventive health mostly: The majority of people, or perhaps the majority of immigrants, do not seek care until they feel pain or can’t walk.”

Participants commented that having health insurance fosters both a sense of self-confidence and of motivation to work and overcome adversity:

“A person without health cannot work, cannot do anything. But if a person is confident of having support, like health insurance, that person has more desire to work and to continue forward.”

Although confusion was pervasive about whether the ACA represented a change in insurance regulations or an insurance product in itself, focus group participants demonstrated basic knowledge of important features of healthcare reform and were able to name key aspects of the law. When asked about changes associated with healthcare reform, participants often mentioned the individual mandate, the employer mandate, non-discrimination against pre-existing conditions, and coverage of children until age 26 under parents’ insurance. Only one participant referred to the concept of an income-based sliding scale for health insurance pricing:

“I have also heard that depending on how much you make, you will pay. If you make a lot you’ll pay a lot, if you make little you pay little. I wonder if those who pay little will get the same services.”

Participants demonstrated little awareness of key mechanisms that make health insurance more affordable or plans more easily comparable. The overwhelming majority of participants were unaware of the cost implications of the Medicaid expansion in Rhode Island – including that insurance would be free for household incomes below 138% of the FPL, and that individuals with incomes below 400% of the FPL would qualify for tax subsidies on a sliding scale. Very few participants were aware of the existence or role of the insurance marketplace or of the notion that insurance plans offered in marketplaces under the ACA are standardized to facilitate product comparisons by customers:

“There has to be one [health insurance marketplace]. [The government] has to be thinking that they have different offices, all of which sell the same. And the government wants to create jobs. There has to be a place to enroll because a lot of people want to enroll.”

Opinions of healthcare reform were mixed among focus groups, specifically with regard to universal health care, cost implications of reform, and implications of quality of care. The vast majority of participants expressed approval of the concept of universal healthcare. When asked about whether the quality of care would improve or deteriorate as a result of the ACA, opinions within focus groups were evenly divided. Several participants viewed quality improvement as a central goal of healthcare reform that would thus be effectively enforced:

“There is going to be good quality. There will be control by a regulatory commission, which will attend to how service is being delivered.”

Other participants were concerned that an increase in the insured population could overwhelm the healthcare system and consequently compromise quality of care. When asked about whether the cost of healthcare would change, most participants anticipated a significant rise in their out-of-pocket combined cost of insurance coverage and services.

Three predominant misconceptions regarding the impact of the ACA emerged within focus group sessions. First, most participants believed that healthcare reform resulted in a significant increase in insurance costs across income groups. Second, many of the participants

were under the impression that undocumented workers could be eligible for insurance benefits under the ACA. Third, several participants feared that healthcare reform would function as a form of social control. Participants in three out of six focus groups mentioned that insurance information would be gathered via skin-implanted “chips”:

“I have heard that instead of having a card, we will have an implanted chip in our skin where all your data can be collected”

One participant reported having a family member in the military participating in a government initiative involving subcutaneous computer chips for medical purposes while many in the group nodded and expressed agreement.

When asked about information needs within the community regarding healthcare reform, participants identified three main categories: eligibility criteria, insurance utilization, and resources for undocumented workers. Most participants had questions about eligibility criteria in relation to income, migration status, and employment status:

“I am not sure if insurance is for residents or citizens. But I think that at least the people that live in the US will have access to health insurance.”

Participants suggested that information campaigns should focus on how to best utilize insurance benefits under the ACA and on providing resources for undocumented workers.

Interviews with Health Insurance Navigators

Health insurance navigators participating in semi-structured interviews reported high motivation to obtain insurance among their Spanish-speaking clientele:

“When [the ACA] first started in October or so, when people were unable to enroll, there wasn’t enough awareness or motivation. But now [prior to the second enrollment period] there is more awareness and motivation.”

However, interview participants identified recurrent knowledge gaps regarding insurance affordability, eligibility criteria, payment structure, insurance use within the first-time insured, and enrollment periods:

“And some people don’t know about other eligibility criteria, like being pregnant, qualifies you regardless of immigration status and that [criteria change] similarly for having children.”

Navigators expressed that most low-income Spanish-speaking clients were surprised about insurance affordability under the ACA:

“I had a woman this morning that thought it could not be real that she was eligible for health insurance never mind free health insurance.”

Navigators also noted a limited understanding among Spanish-speaking clients of payments through health insurance. Health insurance navigators often reported that Spanish-speakers were not familiar with concepts like co-pay, deductible, and coinsurance. According to

navigators, most primarily Spanish-speaking clients were unaware that enrollment for free state insurance is open throughout the year, as opposed to subsidized and unsubsidized plans.

Navigators identified two main misconceptions among their primarily Spanish-speaking clients. First, they identified that clients commonly perceived insurance to be unaffordable for low-income immigrants. Navigators often noted that clients were usually not aware of how to prove legal presence in the US for over five years to be eligible for free insurance or that they could qualify for subsidized insurance if legally present in the US for less than five years:

“And a lot of [immigrants who have been in the US for less than 5 years] have been here and don't know that [they qualify but have to pay]. They assume it's gonna be an extravagant amount of money. [...] [When I tell them the amount], they're shocked. [...] One, she had to pay \$1 something a month. She couldn't believe it.”

Second, navigators reported that clients often thought that applying for ACA benefits could jeopardize renewal of green cards or delay citizenship application processes which, according to law, is not true (Patient Protection and Affordable Care Act, 2010; US Immigration and Customs Enforcement, 2013; Code of Federal Regulations, 2014):

“That is the first question to me: Is this going to have a bearing on my application for becoming a lawful permanent resident or citizen?”

“They are told, while they are doing their paperwork, that if they apply for any state assistance, they will become disqualified and won't be able to become citizens, won't be able to get their green cards renewed. I explain to them, [...] they can't ask for financial help but, as far as medical, they can.”

Health insurance navigators explained that their clients were fearful of becoming linked to government databases because of concerns about increased risk of deportation and delays to immigration application processing, as well as concerns about government control and access to their private information. In terms of barriers to insurance for primarily Spanish-speaking residents of Rhode Island, navigators listed low literacy of preventive medicine, low understanding of the importance of insurance to cover preventive care, financial constraints, and lack of proper work documentation:

“Yes, some of those that have to pay, say, I've had them tell me: 'Well I'm either gonna have food on the table or have insurance'.”

“Some of them haven't had insurance in so long; they have no idea what to do. That they are supposed to have a physical every year and blood work every year. Or a woman that needs a mammogram every year.”

Navigators stated that employers of their clients were at times unwilling to document total work hours, leading to inability to supply proper documentation for insurance enrollment:

“The problem with folks who do not receive pay stubs is the employers don't want to put anything in writing. So the employer does not want to say that they work for them 35 hours a week.”

Additionally, navigators cited shortage of Spanish-speaking navigators, preference for paper-based outreach efforts (i.e., using mailed letters and flyers), and inadequate interpretation as significant barriers to successful outreach to Latino communities.

“[A barrier is] things not being translated into Spanish often, or at least not in a way that makes sense culturally.”

When asked about outreach recommendations to increase insurance rates among Spanish speakers, navigators recommended community-based approaches. To overcome the barrier of mistrust, one navigator suggested that trusted community leaders be trained to educate and refer eligible community members to insurance navigators to complete enrollment:

“We have to get away from our own models of social workers, navigators, providers, front office staff and I think we really need to invest in our communities and look for people who are considered community leaders, people who are trusted in the community. Find some kind of incentive for people. There is a wonderful woman in our community [...]. She's like the Ambassador to Guatemala – she is amazing. She brings every pregnant woman to me, every person with a child to me to make sure the kids get insurance, WIC, know about the food pantries. Those are the people that people trust.”*

**Special Supplemental Nutrition Program for Women, Infants, and Children*

Another navigator's recommendation came from her prior experience that schools should be the primary target for outreach since such spaces often are perceived as less threatening for parents who would hesitate to seek information from officially trained personnel at other sites:

“Reach out at schools, for the parents, because I used to work at school based health centers and that's how we got families in. [...] Especially ones that were coming new because they were afraid to even put their name on anything because they assumed they were gonna be deported if they dare try to apply for anything.”

Another recommendation focused on increasing the number of Spanish-speaking navigators and raising awareness of benefits and eligibility in a culturally aware manner, including using terms and phrases familiar to the most represented nationalities in the state's Latino community rather than translating original flyers into generic Spanish.

DISCUSSION

Understanding barriers to health insurance expansion is crucial to reducing both health and economic inequalities. To better comprehend barriers to coverage under the ACA in Rhode Island's Latino population, our study explored perspectives of Spanish-speaking Latinos through focus groups and perspectives of health insurance navigators through semi-structured individual interviews. Focus group participants displayed basic knowledge of key healthcare reform provisions often mentioning the individual and employer mandates, non-discrimination against

pre-existing conditions, and coverage of children until age 26 under parents' insurance. However, focus group and interview findings implied limited understanding of eligibility criteria for ACA benefits, as well as lack of awareness of Rhode Island's marketplace and of the cost implications of the Medicaid expansion. Interviewed navigators reported that insurance utilization literacy among the first-time insured was often insufficient.

Focus groups and interviews both revealed positive attitudes toward health insurance and healthcare reform, as well as high motivation to seek insurance among primarily Spanish-speakers. Cultural or national origin did not appear to be associated with negative views of allopathic medicine, the US healthcare system, or notions of private and public health insurance. However, government mistrust was a prevalent theme throughout data collection. In focus groups, such mistrust was related to government control and conspiracy theories. In interviews, navigators reported mistrust related to concerns about hindrance of citizenship applications and residence documentation. Navigators identified fearfulness of government-affiliated organizations as an important barrier requiring further attention.

Several of our findings agree with the scarce literature on Latino coverage and insurance expansion. Our study supports prior findings that healthcare reform is necessary but not sufficient to decrease healthcare disparities across race and ethnicity (Zhu et al., 2010). Low literacy regarding insurance affordability, preventive services utilization among the first-time insured, and points of access have been identified as potential contributing factors to coverage disparities (Maxwell et al., 2011). Consistent with prior successful models in Massachusetts (Maxwell et al., 2011), participants in our focus groups and interviews noted that face-to-face interactions with bilingual, trained professionals were the most effective tool to address misconceptions, clarify eligibility criteria, and increase enrollment for Latinos.

Our study accounts for coverage barriers for Latinos in more detail than what has been outlined in prior literature. Interviews noted two highly consequential knowledge gaps in Rhode Island: Spanish-speakers often lacked awareness of how to prove legal presence in the US for the entirety of their residence; and secondly, Spanish speakers legally present in the US for less than five years were not aware of being eligible for subsidized health insurance. Navigators reported the commonly held false notion that green card and citizenship applications for lawful permanent residents could be compromised due to insurance enrollment under the ACA. Because receiving federal aid by enrolling in programs like the Supplemental Nutrition Assistance Program can, indeed, result in citizenship application delays, it is understandable why such misconception might be common. Identifying such information gaps and misconceptions allows evidence-based outreach content to be developed for future interventions and awareness campaigns.

As in other states including Massachusetts, Rhode Island institutions other than the marketplace benefited from grant programs and funding to invest in enrollment and outreach services (Blumberg et al., 2014; Holahan, Rifkin, Lucia, and Keith, 2012; Maxwell et al., 2011). Our findings support lessons from Massachusetts on the importance of ongoing outreach and navigation interventions to raise awareness of eligibility, affordability, and points of access as well as to reduce mistrust, fear, and misconceptions related to immigration in a culturally aware manner. One well-studied and successful Massachusetts intervention that aligns with our findings involved training local Latino leaders as case managers to recruit immigrants via face-to-face invitations, to create referral networks through health agencies and providers, and to provide insurance eligibility education and follow up to individuals and families (Abreu and Hynes, 2009). In addition, our study provides other specific topics that should be part of the focus of outreach interventions: subsidized insurance eligibility for green card and citizenship

applicants, time periods for Medicaid enrollment, and available resources for undocumented workers.

In terms of health policy, comprehensive implementation of the ACA will likely further decrease coverage disparities. While subject to change with the new presidential administration, access to insurance subsidies may remain similar across states per ruling of the Supreme Court, partially offsetting costs for numerous Latinos living in states that opted against running their own marketplace and expanding Medicaid (Blumberg, Buettgens, and Holahan, 2016; Wishner, 2015). Closing the Medicare Part D coverage gap could also mitigate disparities, as Latinos over 60 years of age are among the fastest growing segments of the US population (Kelley, Wegner, and Sarkisian, 2010). The outreach implications of our study could also be applicable to other states and could be considered in reviewing grant applications for outreach and education initiatives. States like Connecticut, Massachusetts, New Hampshire, District of Columbia, Florida, Maryland, Virginia, New Jersey, New York, and Pennsylvania have a similar Latino demographic profile to Rhode Island (Pew Research Center, 2011), though qualitative studies would ideally precede interventions to assess information needs in a state-specific manner.

Use of grant programs to create state-specific, evidence-based outreach initiatives could represent an effective and systematic strategy to lessen inequalities affecting Latinos nationwide. Grant programs should be used to foster recruitment of Spanish-speaking navigators and create community networks able to inform immigrant communities about health insurance affordability, eligibility, optimal utilization, and to address fears of authorities and additional misconceptions. Immigration reform, nonetheless, will continue to play a key role in health disparities in the US. Therefore, supporting reform that increases access to affordable insurance and healthcare for undocumented and documented immigrants with less than 5 years in the US would significantly help numerous families overcome financial and immigration-related barriers.

Limitations

While the results of our qualitative study suggest that Latinos are at risk for suboptimal participation in health insurance acquisition after reform, the limitations of this study should be considered. Qualitative methods provide data on a range of beliefs and behaviors among a small sample of participants. The optimal number of focus groups and semi-structured interviews for a given study remains unknown. We selected our numbers based on recommendations (Kuzel, 1999) and believe that we reached saturation of knowledge, attitudes, and barriers regarding access to healthcare reform among Spanish-speaking Latinos.

Our study's focus group sample consisted primarily of participants from Colombia, the Dominican Republic, and Puerto Rico, all living in Rhode Island. Therefore, certain beliefs and attitudes identified in our study may not be relevant for Latinos with different origins or those living elsewhere in the US. However, the role of language barriers in navigating a new system of insurance benefits may be applied to other communities with limited English proficiency.

A limitation of our study design is that focus group data were collected closely before and early in the first ACA enrollment period. Hence, our focus group findings may reflect a single point in time amid ongoing changes in circumstances and perceptions. However, semi-structured interviews with health insurance navigators closely before the second enrollment period were consistent with findings from our focus groups, providing greater detail on barriers to health insurance for Spanish-speaking Latinos.

One question our study was unable to fully explore during focus groups was the role of immigration status in relation to insurance status. Because this topic is difficult to address in a

recorded group discussion during which researchers need to put participants at ease and gain trust, our group decided to not ask directly. However, our group probed for reasons for not having health insurance in focus groups (see supplemental pages), and navigators were asked directly during semi-structured interviews.

CONCLUSION

Our findings suggest that specific knowledge gaps and misconceptions are likely barriers to insurance expansion among Spanish-speaking Latinos in Rhode Island. Local initiatives, providers, and points of care should be targeting Latinos in a culturally aware manner to inform about affordability and points of access for insurance enrollment, as well as to address misconceptions among documented immigrants. Ongoing assistance for insurance enrollment and navigation of the healthcare system is key to enhancing uptake of health insurance among Rhode Island Latinos. Going forward, our research group envisions using the findings of this study to produce video-based tutorials in Spanish on access to health insurance and optimal insurance utilization, to be distributed via social media, healthcare sites, faith-based communities, social service agencies, and community events in Rhode Island.

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SUPPLEMENTAL PAGES

Question Samples from Focus Groups with Spanish-speaking Latinos:

Section I: Healthcare Reform and Benefits

1. I'd like to start off by asking about what you think of when you hear one of the following: "healthcare reform", "Affordable Care Act", or "Obamacare"?
¿Me gustaría empezar por preguntarle que piensa usted cuando oye uno de los siguientes: "reforma de salud", "Affordable Care Act", o "Obamacare"?
2. What are some new benefits and regulations that you think about as part of healthcare reform? (Customize based on above answers.)
¿En qué nuevos beneficios y regulaciones piensa usted como parte de la reforma de salud?
3. If relevant, probe for non-discrimination against pre-existing conditions
¿Alguien ha escuchado algo en relación a las condiciones pre-existentes?
4. If relevant, probe for qualifying for parental insurance up to the age of 26
¿Alguien ha escuchado si ha cambiado la edad hasta cual los hijos pueden ser cubiertos por el seguro de sus padres?
5. If relevant, probe for whether everyone must be insured or pay a penalty
¿Alguien ha escuchado algo en relación sobre qué pasará si usted no tiene seguro?
¿Alguien ha escuchado algo en relación a una penalidad o multa?

Section II: Access to Health Insurance and the Marketplace

6. What do you think of when you hear the phrase “Health Insurance”?
¿Qué piensa usted cuando oye la frase “seguro médico”?
7. If relevant, probe for experiences with health insurance (i.e., family/friends)
¿Ha tenido usted, un familiar o amigo suyo una experiencia que haya influenciado lo que piensa acerca de los seguros médicos?
8. If relevant, probe for cultural reasons why health insurance might not be appealing
Algunas personas piensan que la medicina moderna o alopática, el sistema de salud tradicional o el sistema de salud estadounidense no son una buena alternativa para mantener o recobrar la salud. ¿Piensa usted algo parecido? ¿Quizás para usted no sea de tanto interés obtener un seguro médico?
9. If relevant, probe for characteristics of people who have or should have insurance i.e., income, healthy, ill, etc.
¿Piensa usted que en general cierto tipo de personas tiene o debe tener seguro médico?
10. If relevant, probe for the consequences of being insured and vice versa
¿Qué consecuencias, piensa usted, están asociadas a tener o no tener seguro médico?
11. If relevant, probe knowledge of types of health insurance:
What have you heard are the differences between Medicaid, Medicare, and Private Health Insurance?
¿Cuáles ha escuchado que son las diferencias entre Medicaid, Medicare y un seguro médico privado?
12. Which types of health insurance have you heard will be changed the by healthcare reform?
¿Qué tipos de cobertura médica ha escuchado que serán cambiados por la reforma de salud?
13. If relevant, probe how coverage expansion will actually work through private insurance
¿Cómo piensa que el seguro privado será más asequible tras la reforma de salud?
14. If relevant, probe for Medicaid Expansion
¿Ha escuchado si más personas serán elegibles para seguro gratuito o para Medicaid?
¿Hasta cuánto puede ganar y todavía ser elegible para un seguro gratuito?
¿Ha escuchado si hasta que ingreso puede tener y todavía calificar para asistencia económica bajo la reforma de salud?
15. If relevant, probe for awareness of Individual and Employer Mandates
¿Ha escuchado si será obligatorio para individuos tener seguro médico o si será obligatorio para ciertas compañías ofrecerlo?
16. If relevant, probe for doughnut hole rebates

¿Ha escuchado si Medicare va a cambiar su política de compensación para la compra de medicamentos?

17. Have you ever had any type of health insurance? Yes/No, If yes, which ones?
¿Ha tenido alguna vez algún tipo de seguro médico? Sí/No, Si sí, cual?

If NO, continue on question 17. If YES, continue on question 22.

18. Have you heard about health insurance but never thought about it much? Why?
¿Ha escuchado usted sobre seguro médico pero no ha pensado sobre ello? ¿Por qué?

19. Have you thought about health insurance but have not decided if you want to get one? Why?
¿Ha pensado en un seguro médico pero no ha decidido que quiere uno? ¿Por qué?

20. Have you decided not to get one? Why?
¿Ha decidido no adquirirlo? ¿Por qué?

21. Have you decided to get one but still haven't made plans? Why?
¿Ha decidido adquirirlo algún día pero no ha hecho planes todavía? ¿Por qué?

22. Have you made plans to get one already but just have not done it yet? Why?
¿Ya ha hecho planes para adquirirlo pero simplemente no lo ha hecho? ¿Por qué?

23. What have you heard about choosing a health insurance plan?
¿Que ha oído usted acerca de escoger un plan de seguro médico?

24. If relevant, probe what comparing plans can be like?
¿Cómo ha sido su experiencia o piensa que es escoger un seguro medico?

25. If relevant, probe for standardization of plans at marketplaces
¿Ha escuchado si los planes de seguro médico serán estandarizados para facilitar la comparación y selección de planes?

26. Have you heard about how you will be able to shop for health insurance under the new healthcare law, or about the Health Benefits Exchange?
¿Ha escuchado sobre cómo podrá usted comprar seguro médico bajo la nueva ley de salud? ¿Ha escuchado sobre un mercado de seguros médicos, o sobre el "Health Benefits Exchange", "Insurance Exchange" o "Insurance Marketplace?"

27. If relevant, probe for role of the Exchange
¿Si alguno, cuál piensa que será el rol del mercado de seguros médicos bajo la reforma de salud?

28. If relevant, probe if you can compare all plans (standardized packages) and learn about what discounts apply to you in one place

¿Piensa que bajo la reforma de salud habrá un lugar donde comparar todos los planes médicos estandarizados y donde puede aprender para qué tipo de asistencia económica para comprar un plan cualifica usted y su familia?

29. If relevant, probe how can this be useful

¿Piensa que un lugar como el que acabamos de describir sería útil?

30. If relevant, probe about internet access, phone access, and physical locality

¿Piensa que puede aprender sobre sus opciones de compra de un seguro médico bajo la reforma de salud a través del teléfono, del internet o en persona? ¿Cuál método le parece a usted más útil?

Section III: Impending Changes in Medical Care Quality and Cost

31. What are your thoughts on how quality or cost of care might change due to expanded coverage?

¿Qué piensa usted sobre como podría cambiar la calidad y el costo del cuidado médico a consecuencia de la expansión de cobertura?

32. If relevant, probe for potential reasons

¿Qué experiencias o razones han influenciado su pensar o su parecer?

33. If relevant, probe for how this might affect decisions to acquire health insurance

¿Cómo cree que sus opiniones influyen su decisión de obtener o no un seguro médico?

34. What aspect of the new healthcare law are you most interested in?

¿En qué aspecto de la nueva ley de salud está usted más interesado?

35. If relevant, probe for personal reasons

¿Por qué le resultan este o estos aspectos más interesante(s)?

Section IV: Wrap- up

36. Is there anything I didn't ask about healthcare reform that you'd like to discuss?

¿Hay algo que no pregunte sobre la reforma de salud que les gustaría discutir?

Question Samples from Semi-structured interviews with Health Insurance Navigators:

Section I: Healthcare Reform Knowledge and Awareness

1. Do you think Spanish-speakers in Rhode Island have a clear sense of what the Affordable Care Act (ACA) is?

¿Cree usted que los hispanohablantes en Rhode Island tiene una idea clara de lo que es el ACA?

2. To what degree do you think people are motivated to acquire health insurance under the ACA?
¿En qué medida, cree usted que la gente está motivada para adquirir seguro médico bajo el ACA?
3. What are some common misconceptions that you have found among individuals who might qualify for ACA benefits?
¿Cuáles son algunas nociones erróneas comunes que usted ha hallado entre personas que podrían calificar para beneficios bajo el ACA?
4. What are some common knowledge gaps among individuals that have not enrolled under the ACA?
¿Cuáles son algunas lagunas de conocimiento común entre individuos que no se han inscrito bajo el ACA?
5. Probe for each question how would the answer differ if referring to the general state population instead of primarily Spanish-speakers in Rhode Island
¿Sería este asunto distinto para el resto de la población del estado? ¿Cómo así?

Section II: Barriers to ACA Enrollment

6. What are some common barriers to getting eligible Spanish-speaking individuals to enroll for ACA benefits?
¿Cuáles son algunas de las barreras comunes para conseguir que individuos hispanohablantes elegibles se inscriban para beneficios bajo el ACA?
7. If relevant, probe specifically for individuals who qualify for free Medicaid insurance
¿Ha notado si existen barreras comunes para aquellos que cualifican para seguro gratuito bajo Medicaid?
8. If relevant, probe specifically for individuals who qualify for tax-credits or subsidies
¿Ha notado si existen barreras comunes para aquellos que cualifican para subsidios o créditos tributarios?
9. If relevant, probe for cultural barriers
¿Ha notado si es común que existan barreras culturales a la hora de inscribirse para seguro médico? ¿Tal vez alguien no crea en la medicina alopática, en el sistema de salud tradicional o en sistema de salud estadounidense?
10. If relevant, probe for linguistic barriers
¿Ha notado si es común que existan idiomáticas a la hora de inscribirse para seguro médico?
11. If relevant, probe for logistic and transportation barriers
¿Ha notado si es común que existan barreras logísticas o de transportación a la hora de inscribirse para seguro médico?

12. If relevant, probe for healthcare reform literacy barriers
¿Ha notado si el conocimiento acerca de la reforma de salud, o la falta del mismo, puede actuar como una barrera?
13. If relevant, probe for financial barriers
¿Ha notado si razones financieras pueden actuar como una barrera?
14. If relevant, probe for security concerns as barriers
¿Ha notado si preocupaciones por seguridad pueden actuar como una barrera?
15. If relevant, probe for political concerns as barriers
¿Ha notado si las creencias políticas pueden actuar como una barrera?
16. If relevant, probe for religious barriers
¿Ha notado si las creencias religiosas pueden actuar como una barrera?
17. Probe for each question how would the answer differ if referring to the general state population instead of primarily Spanish-speakers in Rhode Island
¿Sería este asunto distinto para el resto de la población del estado? ¿Cómo así?

Section III: Recommendations

18. If you were creating a public health campaign to promote insurance rates under the ACA what would be your main message and what pieces of information would you be sure to share to increase enrollment for Spanish-speaker in Rhode Island?
Si estuviera creando una campaña de salud pública para promover las tasas de seguros bajo el ACA, ¿cuál sería su mensaje principal y qué información se aseguraría de compartir para incrementar las inscripciones entre hispanohablantes en Rhode Island?
19. What could the marketplace outreach team do better to increase insurance rates among Spanish-speaking residents of Rhode Island?
¿Qué podría hacer mejor el equipo de divulgación del mercado de seguros para mejorar la tasa de hispanohablantes asegurados de Rhode Island?
20. What could healthcare providers do better to increase insurance rates among Spanish-speaking residents of Rhode Island?
¿Qué podrían hacer los proveedores de salud mejor para incrementar la tasa de asegurados entre los hispanohablantes que residen en Rhode Island?
21. Probe for each question how would the answer differ if referring to the general state population instead of primarily Spanish-speakers in Rhode Island
¿Sería este asunto distinto para el resto de la población del estado? ¿Cómo así?

Section IV: Wrap- up

22. Is there anything I didn't ask about primarily Spanish-speaking Rhode Island residents and healthcare reform that you'd like to discuss?
¿Hay algo que no pregunte sobre los residentes hispanohablantes de Rhode Island y la reforma de salud que les gustaría discutir?

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