Intersectionality and the HIV continuum of care among Latino men who have sex with men in North Carolina

Background
Following the biomedical discovery that achieving viral suppression with anti-retroviral therapy not only benefits individual health but also reduces HIV transmission at the population level (known as “treatment as prevention”), there has been increased attention to improving early diagnosis and facilitating timely linkage to HIV care and retention in care. Latino men in the United States are disproportionately affected by HIV (CDC 2013). In North Carolina (NC), a relatively new immigrant destination, HIV diagnosis rates among Latino men are over two times higher than rates among non-Latino whites and most transmission is attributed to male-to-male sex (NCDPH 2012). The number of reported cases, however, may represent a small fraction of the HIV burden among Latinos due to low rates of testing (Sena et al 2010). Latino men in NC are also over two times more likely to present with a late HIV diagnosis than non-Latinos (Torrone et al 2007). Much less is known about Latino men’s experiences with staying in HIV care in a new immigrant destination. We aim to address this gap by exploring the experience of Latino MSM living with HIV in North Carolina with retention in HIV care and treatment services.

Theoretical Framework
Bowleg et al (2013) define intersectionality as a framework that “asserts that multiple social identities such as race, ethnicity, gender, SES, gender, sexual orientation (to name a few) intersect at the individual level of experience (i.e., micro level) to reflect multiple and interlocking social-structural inequality (i.e., macro level)”. Identities are considered “multiple, interdependent, and mutually constitutive” and health outcomes, such as HIV treatment and care outcomes, should be viewed as the product of these intersecting identities. Viruell-Fuentes et al (2012) invoke intersectionality in their critique of cultural explanations of immigrant health patterns. They directly challenge the widespread use of the individual-level concept of acculturation, and argue for “advancing the scholarly understanding of how factors such as immigration policies, labor practices, neighborhood characteristics, and racialization processes intersect and affect the economic and social integration of immigrants”. These two perspectives on intersectionality focus on both the intersections of identities as well as the intersecting factors at the contextual and structural levels. We seek to apply these two perspectives on intersectionality as an interpretive framework for understanding the determinants of retention in HIV care among immigrant Latino men living in a new immigrant destination.

Methods
For this paper, we are analyzing data from two qualitative studies with Latino MSM living with HIV (n=23) in North Carolina. The first study included life history interviews with 15 Mexican men living with HIV, 7 of which were MSM and are included in the current analysis. We conducted 2-3 interviews with each participant focused on their migration experiences, the evolution of their social networks during migration, and their HIV experiences. The second study included 16 Latino MSM living with HIV to elicit their narratives of HIV testing, linkage to care and retention. Participants in both studies were recruited via referrals from providers and case workers. They were all engaged in some form of HIV care at the time of the interview. All interviews were conducted in the language of choice of the participant (usually Spanish) by a trained, bilingual interviewer. They were transcribed verbatim. Data were analyzed in the original language in which they were conducted.

Our analytic approach was informed by Maxwell and Miller’s (2008) theory of qualitative analysis, which distinguishes between categorizing analysis based on comparisons between participants and connecting
analysis based on trajectories and links within individual stories. We first wrote narrative summaries of each participant’s life and/or HIV story (Lieblich et al 1998). These summaries provide a holistic understanding of how the multiple identities related to being gay, Latino, HIV positive, and (in some cases) undocumented intersect to influence retention in care and treatment. We also used these summaries to develop codes for key themes in the data related to the determinants of retention. Using the Atlas.ti7 software, we systematically coded all of the transcripts. We are currently reviewing the code outputs and developing matrices to facilitate comparative analysis between foreign-born and US born participants among others characteristics. We are also using continuous memo writing to apply the intersectional framework to our interpretations of participants’ experiences staying in HIV care.

Results
In our analysis of Latino men’s experiences with linkages to HIV care and retention in care, we applied an intersectional framework to understand key barriers and facilitators. By using this holistic, intersectional approach, we aim to avoid overly emphasizing “culture” as a determinant of HIV outcomes and to provide greater understanding of the social and structural determinants that are produced by Latino MSM’s intersecting identities.

In their narratives, participants reflected the intersections of their multiple identities (Latino, gay, migrant, HIV-infected, undocumented etc...) in their daily lives in North Carolina. As an example, a 55-year-old participant from Colombia who had recently moved to North Carolina at the time of the interview described the racial and ethnic dynamics among the gay community that he had observed in online communities in North Carolina:

...when I see profiles of people who say that, lots of whites who say “whites only”, lots of blacks who say “blacks only”, many who say no diseases, I don’t want anything to do with these people. Do you understand? I don’t want anything to do with them! It is not possible that, that, that the gays...who have been mistreated for their whole life and are discriminated against so much and between these same people (gays) they are discriminating? This has no....it is just terrible to me.

The consequence of this division was less connection to others and greater social isolation, which can negatively impact retention in care and overall wellbeing.

While all participants were engaged in care at the time of the interview, most had experienced long or short interruptions to their care and treatment. In our analysis thus far, we have identified several specific barriers to retention in care and treatment that lend themselves to being explored through an intersectional perspective including:

Mobility: Participants describe high levels of mobility, between countries and states and also within the state of North Carolina. Most of the recent mobility in the US was driven by a pursuit of work opportunities, especially among undocumented migrants who were usually in the US primarily to look for work and who faced many barriers to maintaining stable employment. Past mobility reflects economic challenges, family problems, joining family members who had already migrated, and a need to escape stigma and discrimination related to sexual orientation. A US-born participant of Salvadoran origin who identified as gay and transgender was homeless and in and out of HIV care at the time of the interview. He described how he lived on the streets starting as a teenager in response to his mother’s rejection,
Umm, growing up in like a Catholic home, my mother wasn’t really, I’m the only gay child. And then on top of that, I’m the only transgendered as they say, so I guess she didn’t really take that too well. So, she would always bicker and stuff like that. I mean, I love her, she loves me, but at the end of the day, it’s something we can’t get along with. I mean, she knows I dress up, she knows I’m gay, but she doesn’t really support it. And because she doesn’t support it, I don’t necessarily get all of the things that I need from her as far as information, and stuff, we don’t communicate. So I have to go to the city to get information about certain programs and look it up on the internet and stuff like that.

Mobility in the past frequently reflected heightened vulnerability to getting exposed to HIV, as reflected in this quote. The more recent mobility posed a direct challenge to retention in care as participants described experiencing gaps in their treatment and care as they changed providers. The same participant quoted above identified his past behaviors and identity as making it hard to get HIV care at the time of the interview,

Okay, why is it so hard to get the care that I need? Um, okay, I feel like it goes into like, growing up. You know what I’m saying? Like as a kid, the community knows me, like I know them, so they got to know me. And, I guess, I messed up when I was younger, I used to steal out of stores, I used to prostitute, you know, I used to live that life. So I guess that doesn’t go too well with a lot of people who probably work in the medical field or probably were doing something, or had a job, and I guess they didn’t take that too kindly. So, I guess that’s probably why I don’t get the same, things that other people do.

A participant from Colombia, where there is a centralized health system, identified the lack of such a system in the US as a major challenge to moving from one location to another without interrupting care.

Documentation status: Documentation status was a cross-cutting factor and “identity” that could also complicate retention in care in several ways. Documentation status was a major barrier to steady employment, which both contributed to economic problems as well as motivated mobility, as mentioned above. One participant described losing his job,

Due to my lack of papers. I used to work a in a restaurant...and I was a really good worker. And my boss took me back to the restaurant (after leaving) and then he had to take me out again because they checked my papers and he told me: ‘get yourself some good ones (papers), get yourself some good ones”. And both of us were fired, we found work in other restaurants, and we were fired there as well.

In addition, participants who were undocumented were perceived to face challenges in light of the recent reforms related to Obamacare. In particular, there was concern that undocumented Latinos would not be able to enroll in the ADAP and Ryan White programs, which were the main sources of public assistance for care and treatment identified by participants.

They um, yeah, it’s mainly, so there’s, the biggest fears are, um, if you’re undocumented, um, the Affordable Care Act doesn’t apply to you, so and, you know ADAP now is kinda being rolled in with, I mean not ADAP, Ryan White money is being rolled into um, into kinda getting people who are HIV positive into the Affordable Care Act and the thing is that Ryan White is what Latinos who are undocumented use.
Participants who were in steady relationships with partners who were American citizens had not been able to consider marriage as an option to obtain legal permanent residency, though some identified this as an option they were considering in light of recent legalization of same sex marriage in NC.

Another major theme related to documentation status was transportation as individuals who lacked documentation were limited in their ability to drive. Many lived far from the HIV clinics where they got care and did not have access to good public transportation, and though some were able to use public transportation without a problem, it required extra planning. For example, participants frequently had to miss an entire day of work to attend their appointments, which meant they were not paid on those days and could also face negative consequences for consistently missing work or if their HIV status was disclosed. Participants also described having to postpone appointments if they could not coordinate their rides or the bus schedules.

**Mental health:** Mental health was a cross-cutting theme that created several challenges to retention in HIV care. One participant simply stated that he had stopped going to appointments in the past, “Cause it’s stressful, like you don’t even want to be bothered.” While some participants spoke of achieving a “normal life” with HIV, many reflected that managing a chronic condition was an emotionally taxing process, in addition to the physical, logistical, and cost considerations. Several participants discussed stopping their medication when they were depressed, though there was a reluctance to apply the label of “depressed” to themselves,

> I stopped going…I have been in a terminal state or dying on three occasions. And the three occasions it has been for not taking my medications, due to emotional problems. I don’t like to use the word depression but it has been my errors, I have abandoned myself, and I tell myself “nothing is wrong”...And I didn’t know that this [stopping my medications] was taking the life out of me, and that at some point I was going to get a major blow. But, it was a lack of...not taking care of myself. It was my ignorance that put me close to death.

This participant resisted the label of depression as a way to explain his dropping out of care and treatment; depression reflects another stigmatizing identity of having mental health problems. Other participants believed that the anti-retroviral medications themselves were causing them to feel suicidal. Several participants described using drugs to cope with the mental burden of living with HIV, which for many was directly connected to living very socially isolated lives due to family rejection based on their sexual orientation and/or having limited social networks in migration destinations.

**Conclusions**

By applying an intersectional framework to the analysis of the narratives of US and foreign born Latino MSM living with HIV in North Carolina, we identified how interruptions in care and treatment were the consequences of both intersecting identities (being gay, Latino, undocumented) and intersecting structural factors (healthcare reform, mobility). This approach can help us to go beyond individual and “cultural” explanations of outcomes along the HIV care continuum among Latinos. Understanding and addressing these issues is critical for achieving the population level prevention benefits of viral suppression through “treatment as prevention” and sustaining optimal health outcomes over the long term.