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Addressing Barriers to Shared Decision Making Among Latino LGBTQ Patients and Healthcare Providers in Clinical Settings

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Abstract

Effective shared decision making (SDM) between patients and healthcare providers has been positively associated with health outcomes. However, little is known about the SDM process between Latino patients who identify as lesbian, gay, bisexual, transgender, or queer (LGBTQ), and their healthcare providers. Our review of the literature identified unique aspects of Latino LGBTQ persons' culture, health beliefs, and experiences that may affect their ability to engage in SDM with their healthcare providers. Further research needs to examine Latino LGBTQ patient–provider experiences with SDM and develop tools that can better facilitate SDM in this patient population.

Keywords: barriers to care, clinical care, health disparities, intersectionality.

Introduction

Shared decision making (SDM) occurs when patients are actively involved with their healthcare providers in decisions about their healthcare, and includes information-sharing, deliberation, and decision making about treatment plans.[1] Effective SDM has been positively associated with patient satisfaction, quality of care, and health outcomes.[2,3] Little is known about the SDM process between patients who identify as lesbian, gay, bisexual, transgender, or queer (LGBTQ), and their healthcare providers; moreover, there is sparse literature on communication and SDM for patient populations at the intersection of race/ethnicity and LGBTQ status.[4,5] Intersectionality provides a framework to understand the intersection of multiple social identities at the individual and social–structural levels.[6] An approach that acknowledges the intersectional nature of different social identities is critical to successful SDM for Latino LGBTQ patients.[7,8] However, to date, there is limited literature that examines the experience of SDM among LGBTQ patients who are Latino, which is especially important as these patients may face unique challenges, such as traditional perceptions of masculinity, limited English proficiency (LEP), and undocumented status, which can affect patient–provider communication, irrespective of the health conditions for which they are seeking medical care.[9–11] In this perspective article regarding the care of Latino LGBTQ patients, we review the current literature, to date, concerning SDM, provide practical advice to providers, and develop an agenda for research.

Literature Review

Details on the search terms and strategy we used to conduct the literature review are listed in Supplementary Appendix 1, Supplementary Tables S1–S3, and Supplementary Fig. S1 (Supplementary Data are available online at www.liebertpub.com/lgbt). After a systematic review of 1,954 articles, we found no empirical studies that focused on SDM with Latino LGBTQ patients. However, we identified 16 articles that met some, but not all, of our inclusion criteria. Although our systematic review revealed no studies examining SDM among Latino LGBTQ populations, the ''near-miss'' articles highlighted important factors that could affect SDM between Latino LGBTQ patients and their healthcare providers. The themes presented below are based on a priori categories found in the Latino cultural competency literature and per our systematic review of the literature. We describe several social and cultural barriers that could impede SDM

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between Latino LGBTQ patients and their providers. We also provide tips to providers who wish to optimize SDM with Latino LGBTQ patients in clinical settings (Table 1).[12–14]

Critical Considerations in SDM with Latino LGBTQ Patients

Limited English proficiency

In 2010, Spanish speakers accounted for nearly 66% of all LEP individuals in the United States.[15] The National Standards for Culturally and Linguistically Appropriate Services in Health Care has issued recommendations for culturally competent care, interpreter services, and organizational support; however, it is unclear how adherent health systems are to these regulations.[16,17] Lack of open communication between LEP patients and health providers may prevent information sharing (e.g., disclosure of gender identity or sexual orientation) and/or deliberation about treatment options—key tenets of SDM.[18–20] Family or friends of LEP Latino patients often act as translators in clinical encounters, which may impede patients from discussing sexual orientation and/or gender identity with their provider if they had not previously disclosed to their family and friends first.

Documentation status

A report from The Williams Institute estimates that, ''71% of undocumented LGBT adults are Hispanic.''[21] This population is one of the most vulnerable in our society because it includes individuals at the intersection of multiple marginalized social identities.[22] As a result, many undocumented Latino LGBTQ patients experience additional barriers that prevent them from accessing medical care and building trusting relationships with providers; these barriers can reduce opportunities to engage in high-quality communication and SDM. Such barriers include fear of deportation, not wanting to disclose immigration status to providers when seeking services, inability to take days off from work to attend medical appointments, lack of access to immigrant friendly services/referrals, and difficulties meeting paperwork requirements due to lack of proper identification or proof of income.[7,23,24]

Religious beliefs

Faith and religion often play integral roles in Latino patients' decisions regarding health and medical treatment.[25] Latino LGBTQ patients who have strong religious ties may experience cognitive dissonance between faith and identity, which may, in turn, affect disclosure of sexual orientation and gender identity to providers whom they perceive to be religious. Erosion in patient–provider trust due to assumptions about providers' religious beliefs, and internalized religious conflict, may hinder communication and SDM behaviors among Latino LGBTQ patients.

Family stigma and social support

Familism, a cultural value defined by familial support, emotional interconnectedness, and familial honor, has been shown to be critical among Latinos.[26] Among LGBTQ Latinos, strong family connections and friend networks are associated with a positive sense of self.[27] Latino LGBTQ patients may be forced to make medical decisions on their own without the family support that they may prefer to have, subsequently decreasing patients' self-efficacy and increasing their reliance on providers in the decision-making process. SDM may be further jeopardized when providers refer patients to community or social services that are not LGBTQ *and* Latino friendly, thus reducing the nonfamilial support that such patients have access to and limiting implementation of shared treatment plans. Alternatively, Latino LGBTQ patients may opt out of healthcare altogether because of a lack of familial support. One study found that Latino men who have sex with men (MSM) who felt stigmatized by their family were less likely to maintain regular HIV care.[28]

Traditional expectations of masculinity

The Latino cultural value of ''machismo'' is an idealized form of masculinity that could be either positive (e.g., assertiveness and courage) or negative (e.g., violence and sexual aggression toward women).[29,30] Identifying as gay may not be acceptable within Latino culture because of stereotyped perceptions about gay men being less masculine. When taking a sexual history, providers should remember that Latino MSM may not identify as gay or bisexual.[12] Once patients disclose their sexual and gender identities, providers should use the labels with which the patients identify, which can help patients trust the provider and facilitate information sharing.

Alternative therapies

The use of herbal and folk therapies may also affect healthcare decisions for many Latinos. A survey of 152 HIV-positive Latino gay and bisexual men found that those who used complementary and alternative medicine were less likely to keep doctors' appointments, to follow doctors' instructions, and to adhere to their medication regimen compared to Latinos who did not use these therapies.[31] In a study of Hispanics diagnosed with colorectal cancer, of 631 Hispanic patients surveyed, 40% of patients reported use of complementary and integrative health (CIH) approaches. However, the majority (76.3%) was reluctant to speak with their physician regarding their CIH use.[32] Thus, providers need to be open-minded and ask their Latino LGBTQ patients about their use of alternative therapies and become familiar with these therapies to facilitate SDM around treatment options.

Traditional perception of the patient–doctor relationship

''Personalismo,'' a desire for a formal friendliness, can influence the patient–doctor relationship.[33] Latino patients, who often perceive that the patient–doctor relationship is paternalistic, may be concerned that asking questions and for clarification may affect their relationship with their healthcare providers adversely. Furthermore, Latinos may be more willing to defer healthcare decisions to their providers.[34,35] While no studies have assessed the importance of personalismo and paternalism in LGBTQ Latino perceptions of the patient–doctor relationship, such concepts may still be pertinent.

Diversity among the Latino LGBTQ population

Although many Latinos share core cultural values, physicians should be aware of the significant diversity and heterogeneity among this population in terms of their countries of origin, religious beliefs, educational attainment, and acculturation.[13] Few studies with LGBTQ Latinos have taken into account this

Table 1. Considerations for Providers Caring For and Practicing SDM with Latino LGBTQ Patients

Domains	*Impact on SDM*	*Practical tips for providers*
LEP	• Lack of open communication between LEP LGBTQ patients and health providers may prevent information sharing (e.g., disclosure of gender identity or sexual orientation) and/or deliberation (e.g., discussion of complex medical conditions), key tenets of SDM.	• Offer professional interpreter services that are culturally and LGBTQ competent. • When professional interpreters are not available, do not use family members or friends as interpreters without checking with the patient first. Some LGBTQ Latino patients might not be ''out'' to their family or friends and would prefer to not disclose or discuss their sexual orientation, gender identity, or specific aspects of their health in front of them.
Documentation status	• Undocumented status could be an important barrier to accessing services and building trusting relationships with providers, which can reduce Latino LGBTQ patients' opportunities to engage in high-quality communication and SDM.	• When Latino LGBTQ patients disclose undocumented status, ask if they have any issues or concerns that could affect their ability to continue with care/attend follow-up appointments (e.g., being in deportation proceedings, being unable to take days off from work to attend medical appointments, or having difficulties meeting paperwork requirements due to lack of proper identification or proof of income). • Receptionists and other clinical staff should be culturally competent when talking with undocumented patients (e.g., avoid asking patients why they don't have a social security number or a driver's license in front of other patients). • Intake forms should make the social security number field optional if possible. • Add a question to your intake forms asking patients to disclose their immigration status, while reassuring them that their information will remain confidential. • Do not assume that all Latino LGBTQ patients are undocumented. However, be prepared to provide resources if a patient discloses that they are undocumented. • Verify that referral organizations are immigrant friendly and LGBTQ competent.
Religious beliefs	• Erosion in patient–provider trust due to assumptions about providers' religious beliefs and internalized religious conflict may hinder communication and SDM behaviors among Latino LGBTQ patients.	• Create a safe and welcoming space regardless of your own religious beliefs/values or the perceptions you may hold about Latino LGBTQ patients' religious beliefs. • Be open-minded to facilitate trust and information sharing.
Family stigma and social support	• Latino LGBTQ patients may be forced to make medical decisions on their own without family support that could decrease patients' self-efficacy and increase their reliance on providers in the decision-making process. • Referring patients to community or social services that are not LGBTQ *and* Latino friendly could limit implementation of shared treatment plans.	• Ask the patient who within the family system is aware of his/her sexual orientation and gender identity, to assess the level of support they might have. • Be aware that Latino LGBTQ patients who do not have support from family members may not want to involve them in the decision-making process. • Offer referrals to community services that are Latino and LGBTQ competent.
Traditional expectations of masculinity	• Many Latino men who have sex with men may not identify as gay due to ''machismo'' within Latino culture. • Using the labels that patients identify with can encourage patients to trust the provider and facilitate information sharing.	• When taking a sexual history, remember that Latino MSM may not identify as gay or bisexual.[12] • Ask patients about sexual orientation, sexual behavior, and gender identity and use the labels that patients identify with to create a welcoming space/environment.

(*continued*)

Table 1. (Continued)

Domains	*Impact on SDM*	*Practical tips for providers*
Alternative therapies (e.g., the use of herbal and folk therapies)	• The use of herbal and folk therapies may affect healthcare decisions for many Latino LGBTQ patients (e.g., keeping doctors' appointments, following doctors' instructions, adhering to treatment).	• Ask Latino LGBTQ patients about their beliefs about and use of alternative therapies in an open-minded and nonjudgmental way. • Become familiar with alternative therapies to encourage SDM around treatment options.
Traditional perception of the patient–doctor relationship	• While no studies have assessed the importance of personalismo and paternalism in LGBTQ Latino perceptions of the patient–doctor relationship, these concepts may still be pertinent. • Many Latinos hold traditional beliefs regarding roles of patients and providers and are more willing to defer healthcare decisions to their providers.	• Actively encourage Latino LGBTQ patients to participate in information sharing, deliberation, and decision making. • Reassure Latino LGBTQ patients that their patient/provider relationship and medical care will not be affected adversely if they disagree with medical recommendations. • Equalize the power imbalance found in a traditional patient–doctor relationship to make Latino LGBTQ patients feel comfortable when participating in SDM
Diversity among the Latino LGBTQ population	• When patients feel that their providers respect their values, beliefs, and preferences, they often feel more comfortable engaging in information sharing, deliberation, and SDM.	• Do not assume that all Latino LGBTQ patients share the same cultural beliefs and practices. • Be aware of the significant diversity and heterogeneity among the Latino population in terms of their countries of origin, religious beliefs, educational attainment, and acculturation.[13] • Understand the differences among various LGBTQ subpopulations as their healthcare experiences and needs can also be different.[14] • Use a patient-centered approach to SDM to explore Latino LGBTQ patients' experiences and core values without making assumptions based on predominant stereotypes.

LEP, limited English proficiency; LGBTQ, lesbian, gay, bisexual, transgender, or queer; SDM, shared decision making.

Table 2. Areas Needing Research in SDM Among Latino LGBTQ Patients

Overall
- Specifically examine the impact of intersecting multiple minority identities when studying SDM with Latino LGBTQ and other multiple minority patients
- Provide analysis by racial/ethnic subgroup and/or intersection of race/ethnicity with sexual identity
- Ensure that all LGBTQ populations are represented in future research studies as each group has unique healthcare experiences and needs[14]

System level
- Develop and test tools to improve Latino LGBTQ SDM

Provider level
- Explore how providers' perceptions and experiences influence SDM with their Latino LGBTQ patients
- Develop and test cultural competency training for providers in caring for Latino LGBTQ and other multiple minority patients

Patient level
- Evaluate the experiences of Latino LGBTQ patients in participating in SDM with their healthcare providers
- Conduct studies on SDM that focus on Latina lesbian and bisexual women, and transgender patients, since these populations are particularly underrepresented in the literature
- Focus on SDM across health conditions that affect Latino LGBTQ patients disproportionately (e.g., obesity, intimate partner violence, mental health)

diversity. While one survey of HIV-positive men residing in the U.S. from South America and Puerto Rico found that the groups were fairly consistent in terms of condom use and disclosure of seropositive status,[36] others have found that less acculturated Latinos (Spanish-speaking or foreign born) have lower levels of HIV disclosure compared to English-speaking Latino men.[37] As LGBTQ patients are also heterogeneous, it is important that providers understand the differences among various LGBTQ subpopulations as their healthcare experiences and needs can also be different.[14] A patient-centered approach to SDM can allow healthcare providers to explore Latino LGBTQ patients' experiences and core values without making assumptions based on predominant stereotypes.

Illustrative Case Study

We created a hypothetical case study to illustrate the intersectional issues that can occur in real-life patient–provider encounters among Latino LGBTQ patients.

Laura S. is a 54-year-old cisgender* Latina born in Colombia and has lived in the U.S. for 20 years. She comes to clinic for a follow-up on her weight. The physician is a second-generation Mexican American who does not speak Spanish fluently, so the encounters are always in English. The patient is mainly Spanish-speaking and tries her best to communicate in English in her visits. Her exam is unremarkable except for a BMI of 32 and several bruises of different stages on her shoulders and upper arms. There is concern for potential intimate partner violence. Upon questioning, the clinician learns that the patient has a female partner who has been physically abusive and has threatened to ''out'' the patient to her family. Unknown to the provider, the patient is concerned that her undocumented status may cause legal problems if she reports her intimate partner abuse or seeks services. The physician provided the patient with printed material listing phone numbers of local domestic violence shelters. The encounter ended with no follow-up appointment scheduled.

*The term cisgender is used to describe a person whose gender identity corresponds to the expectations of others based on the sex they were assigned at birth.

This patient case demonstrates the difficulties that Latino LGBTQ patients may face when making decisions with their providers. In terms of *information sharing*, the patient did not readily disclose being a victim of intimate partner violence, being a lesbian, or being undocumented to her provider. The provider may need to ask the patient about her sexual identify in a nonjudgmental and routine manner. In this case, the provider had not inquired about the patient's sexual identity before this visit. The use of an interpreter may help overcome communication barriers that the patient may have due to her LEP. The provider could have inquired whether she would prefer to have an interpreter present for the clinical encounter to help facilitate communication. In terms of *deliberation* and *decision making*, the patient is fearful of accessing resources or services because she does not want to disclose her immigration status to her physician and, perhaps, is unsure if resources in the community are culturally and linguistically tailored to her needs. Assuring patients from the start that their documentation status will remain confidential may be one way to facilitate patient disclosure. Vetting community resources to assure they are Latino and LGBTQ friendly is important in placing referrals.

Conceptual Model for SDM Among Latino LGBTQ Patients

In a previously published review, Peek et al. describe a conceptual model of SDM among LGBT African Americans.[8] Their model describes how social identity and perceptions of social identity inform SDM between patients and physicians. This model can be readily adapted to Latino LGBTQ patients with the addition of domains that are unique to Latinos. LEP, undocumented status, traditional expectation of masculinity, religious beliefs, family support, use of alternative therapies, traditional view of the patient–doctor relationship, and diversity among Latinos not only affect how patients perceive themselves but also the way a provider may perceive the patient. As described above, these domains can have a direct impact on patient–provider communication, trust, and decision-making preferences, thus ultimately affecting SDM.[8]

Research Gaps

Through our synthesis of the literature, we identified areas that need further study to examine Latino LGBTQ patients' experiences with SDM (Table 2), including assessment of tools to improve Latino LGBTQ SDM and the testing of cultural competency training for providers. Most studies found on Latino LGBTQ patients were focused on MSM and HIV. We found no studies that focused on Latina lesbian or bisexual women, or transgender patients. Thus, all LGBTQ populations need to be represented in future research studies as each group has unique healthcare experiences and needs.[14] In addition, more studies need to focus on other health conditions that affect Latino LGBTQ patients disproportionately (e.g., obesity, intimate partner violence, and mental health).[18,30]

Conclusions

Latino LGBTQ patients face many barriers to SDM with their providers. Providers caring for Latino LGBTQ patients can optimize SDM in clinical settings by (1) offering professional interpreter services that are culturally and LGBTQ competent, (2) being sensitive to issues around disclosure of documentation status, (3) verifying that referral organizations are Latino, immigrant and LGBTQ competent, (4) creating a safe space regardless of their or the patients' religious beliefs, (5) being aware that patients may have varying social support from family members, (6) using sexual orientation and gender identity labels with which patients identify, (7) asking patients about their beliefs about and use of alternative therapies in an open-minded and nonjudgmental way, (8) actively encouraging Latino LGBTQ patients to participate in information sharing, deliberation, and decision making, and (9) being aware of the significant diversity among the Latino LGBTQ population.

In addition, there are major areas that need further study to examine Latino LGBTQ patients' experiences with SDM, including assessment of tools to improve Latino LGBTQ SDM and testing of cultural competency, and SDM training for providers. Future research should include Latina lesbian and bisexual women, and transgender patients who are underrepresented in this literature and explore other health conditions, beside HIV, which affect Latino LGBTQ patients disproportionately. Finally, research must acknowledge that the healthcare experiences based on LGBTQ status may be different among subpopulations.

As multiple minorities, Latino LGBTQ patients experience health disparities across several conditions and face social challenges that may affect patient–provider communication and SDM. Using an intersectional approach, we can find ways to facilitate SDM and care delivery for Latino LGBTQ patients to improve healthcare and health outcomes among this vulnerable population.

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