

Shared Decision Making Among Clinicians and Asian American and Pacific Islander Sexual and Gender Minorities: An Intersectional Approach to Address a Critical Care Gap

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Abstract

Shared decision making (SDM) is a model of patient-provider communication. Little is known about the role of SDM in health disparities among Asian American and Pacific Islander (AAPI) sexual and gender minorities (SGM). We illustrate how issues at the intersection of AAPI and SGM identities affect SDM processes and health outcomes. We discuss experiences of AAPI SGM that are affected by AAPI heterogeneity, SGM stigma, multiple minority group identities, and sources of discrimination. Recommendations for clinical practice, research, policy, community development, and education are offered.

Keywords: Asian American and Pacific Islander (AAPI), intersectionality, sexual and gender minorities (SGM), shared decision making (SDM).

Introduction

SHARED DECISION MAKING (SDM) is a model of patient-provider communication that encompasses interpersonal processes of *information sharing*, *deliberation*, and *decision making* that ultimately facilitate *trust*, *self-efficacy*, *understanding*, and *satisfaction*.^{1,2} SDM is associated with improved health outcomes, but racial/ethnic minority patients face barriers to engaging in SDM, including providers' misperceptions of patients, patients' mistrust of providers, and the power differential between them.¹⁻³ Mounting evidence shows the effects of providers' automatic and unconscious race-based biases on SDM and subsequent racial disparities in patient health outcomes.^{4,5} Independent of other factors, patients' race or ethnicity can influence providers' beliefs and expectations about patients.⁶ Racial and ethnic minority patients, especially those not proficient in English, are less likely than White patients to engender empathy from and to establish rapport with physicians, and are less likely to receive pertinent information or to be encouraged to engage in SDM.⁷

Scant evidence is available on the role of SDM in the health outcomes of racial and ethnic minorities who are also sexual and gender minorities (SGM), including, but not limited to, those who identify as lesbian, gay, bisexual, transgender, queer, questioning, intersex, or asexual, as well as men who have sex with men and women who have sex with women. Individuals who are both racial and sexual minorities may experience multiple forms of discrimination and may often be overlooked in research.^{8,9} This is the case for Asian American and Pacific Islander (AAPI) SGM, who are often missing from studies concerning racial/ethnic minorities or SGM because AAPI SGM may not be considered prototypical of either group.¹⁰

AAPIs are the fastest growing U.S. population in the last decade.¹¹ Undocumented AAPIs are more likely than any other racial/ethnic group to report being SGM.¹² AAPIs represent a group that varies tremendously in income, employment, education, English proficiency, and health status, all of which are influenced by factors related to generational status, immigration, culture, and geography.¹³ AAPI SGM experience high incidences of high-risk substance use, sexual risk behaviors, and

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mental disorders such as depression, anxiety, post-traumatic stress disorder, and suicidality.^{14–18} It remains unclear how SDM may contribute to or ameliorate health disparities among AAPI SGM. For example, after a review of 1,868 articles, we found *no* empirical studies of SDM with AAPI SGM.

An Intersectional Approach to Understanding SDM

Understanding the relationship between SDM and health outcomes for AAPI SGM requires an intersectional approach that considers how multiple systems of social stratification, including race, ethnicity, sexuality, gender, socioeconomic status, and immigration history, interact to affect the lives of AAPI SGM.^{19–21}

Guided by a SDM conceptual model,³ we identify common experiences of AAPI SGM that fall into three themes: (1) AAPI Heterogeneity, (2) SGM Stigma, and (3) Multiple Minority Group Identities and Sources of Discrimination (Table 1).^{4–8,10,12,13,18,22–41} We created three case studies to illustrate the intersectional issues that can occur in real-life patient-provider encounters among AAPI SGM. We outline potential strategies for clinics and clinicians to improve cultural competency, communication, and SDM (Table 2).^{22–26,34,35,38–40,42–46} Finally, we recommend research, policy, community development, and education actions to mitigate SDM barriers for AAPI SGM (Table 3).

Illustrative Case Studies

Case study 1: Effects of stereotypes in delayed diagnosis

Amit is a 37-year-old Indian immigrant cisgender man who has sex with men and women. His early socialization imparted him with the stigma that being gay is a “Western disease,” so he is not out to his family or friends. Amit has not disclosed his sexual behavior to his provider for fear that his provider will out him to his community.

Amit’s regular physician, Dr. Mary, a 52-year-old straight White cisgender woman, receives results from routine sexually transmitted infection (STI) tests she had ordered. Amit is shocked to learn that he is newly diagnosed with HIV. He had not believed that he was at risk.

Dr. Mary prescribes antiretroviral therapy and refers him to a specialty HIV clinic located in a prominent gay district, with which he is unfamiliar. Amit is pessimistic regarding therapy, and he is anxious and depressed by thoughts of having to disclose his serostatus to his family and friends.

Case 1 illustrates ways that multiple minority statuses of ethnic identity, immigration status, same-sex behavior, and HIV serostatus intersect, and how social structural forces (cultural norms, ethnic stereotypes, heteronormativity, and HIV stigma) are barriers to SDM processes of information sharing and decision making (Table 1). Amit was reticent to disclose his same-sex activity due to stigma, family expectations, and cultural emphasis on the family rather than the individual.

Dr. Mary missed opportunities for prevention because she assumed that Amit was straight and at low-risk for HIV. Indeed, providers may see AAPI patients as being at lower risk for HIV infection due to the “model minority” stereotype of AAPIs engaging in ideal behavior despite evidence to the contrary.^{9,27–29} Because Dr. Mary did not solicit Amit’s preferences, she referred him to a prominent HIV

clinic without considering its location in relation to his distress of being “outed” (Table 1) and of disclosing serostatus, which would force him to contend with antigay sentiments and stigma within his racial/ethnic community.⁴⁷ SGM of color may avoid SGM communities because they do not openly identify as SGM or because these communities are often predominantly White. They may, therefore, be unaware of resources that exist in SGM communities.

Case study 2: Providers’ presumptions and patients’ culturally based expectations

Michelle is a second-generation 53-year-old Taiwanese queer-identified cisgender woman in a long-term relationship with a cisgender woman. Michelle is not out to her family due to stigmatization within their AAPI community.

Michelle’s new physician is Dr. Steve, a 45-year-old straight African American cisgender man. When he asks if she is sexually active, Michelle affirms. Upon examination, it becomes clear that Michelle has not had penetrative intercourse and that the examination is painful. Alarmed, Dr. Steve quickly ends the examination. He concludes that Michelle is not sexually active, but rather that she is naive and limited in English proficiency. He does not provide sexual health/risk-reduction counseling or STI testing. He recommends reference materials on sexuality and reproductive health in her native language. Although confused, Michelle is deferential and allows the appointment to end.

Case 2 illustrates how differences in culturally based expectations of the patient-provider relationship introduce barriers to SDM processes of information sharing and deliberation. To some, Michelle appears to lack agency and empowerment. However, AAPI SGM may share cultural expectations that support an authoritarian relational structure in patient-provider relationships.^{32,48}

Dr. Steve may have attributed Michelle’s confusion to a lack of English proficiency because of heteronormative assumptions, as well as the implicit racial bias and sentiments that AAPIs are “perpetual foreigners.”³⁰ Sentiments that AAPIs are “not American enough” prevail throughout U.S. history and continue to influence social interactions today (Table 1).³⁰ Despite strong verbal commitments to egalitarianism, even diverse groups of Americans have associated Asians as being less “American” than Whites.³¹

Case study 3: Humiliation, anxiety, and subsequent mistrust

Tik is a 25-year-old undocumented Laotian trans man. Despite his fear of deportation, Tik accessed regular health-care and has been injecting testosterone since transitioning. Because his physician was trans-competent and nonjudgmental, Tik felt comfortable in the ethnically diverse clinic. Recently, Tik had to transfer to another clinic known for serving the SGM community. His new provider, Dr. Molly, is a White lesbian cisgender woman.

Tik is uncomfortable around Dr. Molly, who refers to him as “her,” despite his requests to use male or gender-neutral pronouns. When Tik discloses that he has multiple concurrent sexual partners, he feels heavily judged by Dr. Molly, who views his behavior as high risk and irresponsible. He does not disclose his immigration status for fear of further antagonizing Dr. Molly and being denied treatment.

TABLE 1. INTERSECTIONAL DIMENSIONS AND ISSUES AMONG ASIAN AMERICAN AND PACIFIC ISLANDER SEXUAL AND GENDER MINORITIES

<i>Dimensions of AAPI SGM intersectionality</i>	<i>Pertinent issues</i>	<i>Possible effects and outcomes on shared decision making</i>
Heterogeneity of AAPI SGM	<p>Immigration experiences (e.g., documentation, generational status, trauma)^{10,13,22,23}</p> <p>Acculturation^{10,23,24}</p> <p>Socioeconomic status, class</p> <p>Ethnicity and culture (e.g., role of non-western medicine, religion, and spirituality)^{22,25,26}</p> <p>Language proficiency and health literacy^{22,25,26}</p> <p>Racial stereotypes (e.g., “model minorities” against whom other racial minorities should be compared; “perpetual foreigners” who are never American enough)^{27–31}</p>	<p>Patients</p> <p>Lack of access to AAPI SGM-specific resources^{32,33}</p> <p>Language barriers in communication with providers^{7,33,34}</p> <p>Culturally specific norms, beliefs, and attitudes about privacy, family obligations and expectations, and relationships with authorities and experts¹⁰</p> <p>Fear of deportation or detention¹²</p> <p>Cultural fatalism and perceived lack of treatment efficacy²²</p> <p>Providers</p> <p>Presumptions based on race or ethnicity (e.g., underestimation of risk in stereotyped model minority populations)^{4–6,8}</p> <p>Aggregating AAPI instead of noting differing customs and experiences that may vary by ethnicity^{10,13}</p> <p>Unconscious biases that lead to misinterpretation of health information^{4–6,8}</p> <p>Communication barriers (e.g., limited English proficiency and health literacy)⁷</p>
AAPI SGM stigma	<p>Fear of prejudice and rejection^{27–29}</p> <p>Internalized racial and anti-SGM prejudice^{27–29}</p> <p>Fear of being outed^{27–29,35}</p>	<p>Patients</p> <p>Lack of trust leading to non-disclosure of health information, sexual orientation, and/or gender identity^{22,25,26}</p> <p>Pessimism regarding treatment efficacy, self-efficacy due to SGM stigma</p> <p>Low engagement in care^{22,25,26}</p> <p>Loss to follow-up^{22,25,26}</p> <p>Providers</p> <p>Erroneous presumptions based on race/ethnicity, gender^{4–6,33,36,37}</p> <p>Erroneous presumptions based on sexuality (e.g., overestimation of risk)^{25,36,37,39–41}</p> <p>Unconscious biases and nonverbal behavior leading to shaming and other discriminatory behavior during interpersonal interactions^{25,35,36,38–40}</p>
Multiple minority group identities and sources of discrimination	<p>Isolation from both SGM and heterosexual AAPI communities^{27,41}</p> <p>Racial and sexual stereotypes (e.g., emasculated, submissive Asian man) and exoticization (e.g., submissive Asian woman; sex worker)^{18,22,25,27,41}</p> <p>History of racial exclusion and discrimination (e.g., Chinese Exclusion Act, Page Act, Japanese internment, and Vincent Chin)⁸</p> <p>Conflict with cultural norms (e.g., continuation of blood lines, filial piety)^{18,27,41}</p>	<p>Patients</p> <p>Lack of trust leading to nondisclosure of health information, sexual orientation, and/or gender identity^{22,25,26}</p> <p>Pessimism regarding treatment efficacy, self-efficacy due to SGM stigma</p> <p>Low engagement in care^{22,25,26}</p> <p>Lack of health education and public health messaging targeting multiple minority identities^{22,25,26,38–40}</p> <p>Providers</p> <p>Erroneous presumptions based on race/ethnicity, gender, and sexuality^{4–6,33,36,37}</p> <p>Unconscious biases and nonverbal behavior leading to shaming and other discriminatory behavior during interpersonal interactions^{25,35,36,38–40}</p>

AAPI, Asian American and Pacific Islander; SGM, sexual and gender minorities.

TABLE 2. PRACTICAL TIPS AND RESOURCES FOR CLINICS AND CLINICIANS WORKING WITH ASIAN AMERICAN AND PACIFIC ISLANDER SEXUAL AND GENDER MINORITIES

Domain	Tips and resources for clinics and clinicians
Establishing a safe environment	<p>Terminology and patient intake form Ask for “gender” and “sex assigned at birth.”^{38,39} Ask for “relationship status” rather than marital status and include options such as “partnered.”^{38,39} Ask for “preferred pronoun” and “preferred name.”^{38,39} Use the terms that people use to describe themselves and their partners.^{38,39} Apologize for mistakes in terminology.³⁹</p> <p>Disclosure of sexual orientation and gender identity Indicate a nonjudgmental approach to SGM identities.^{38,39} Elicit sexual orientation and gender identity information in a culturally competent manner.^{35,40} Avoid assuming an opposite sex partner or spouse. For example, instead of: “Do you have a boyfriend or husband?” Ask: “Are you in a relationship?”^{38,39} Assure AAPI SGM patients of their confidentiality.^{38,39}</p> <p>Language and communication Provide SGM materials and services in AAPI languages, dialects, and texts (e.g., traditional written Chinese differs dramatically from simplified written Chinese).²⁵ Ensure access to medical interpreters.</p> <p>Physical environment Display visual cues that depict AAPI SGM to demonstrate awareness and a welcoming approach.³⁹ Designate gender-neutral bathrooms.^{38,39}</p>
Understanding patients’ AAPI SGM identities	<p>Understanding patient background in history taking Allow patients to self-identify in terms of their race, ethnicity, gender, and sexual orientation. Ask patients how being AAPI and SGM have affected them and their interaction with healthcare providers and clinic staff.⁴⁰ Recognize that disclosure of sexual orientation and gender identity may be particularly difficult for AAPI patients.^{22,39} AAPI SGM vary widely by English proficiency, socioeconomic status, and generational status.^{22,25,26} Health deteriorates with longer residence in the United States and over generational status among AAPIs, although the behavioral mechanisms underlying this relationship remain unclear.^{23,24,42} AAPI SGM may have mixed-race or multiracial identities. Ensure the availability of language translation services. Inquire about the possible use of complementary and alternative medicine.</p> <p>Stereotypes Continually examine your own automatic biases about AAPI.²⁵ Be aware of stereotypes about accents, language, body size, model minority status, and/or sexual exoticization and how they can deleteriously impact care.^{34,43} Understand the basic history of discrimination against AAPI and SGM in the United States.^{44–46}</p>

Humiliated and infuriated, Tik leaves the clinic. Afterward, he anxiously realizes that Dr. Molly had an incorrect low dosage for testosterone. He begins to mistrust providers to respect his best interests.

Although Tik has since found a new provider, he does not inject the level of testosterone prescribed to accumulate a reserve to have on hand.

Tik had both positive and negative experiences with providers around the SDM processes of information sharing, deliberation, and decision making (Table 1), leading to different results in the SDM outcomes of trust, self-efficacy, understanding, and satisfaction.¹ When providers allowed Tik to participate in SDM in a judgment- and presumption-free setting, there were high levels of trust and satisfaction. In contrast, Tik’s interaction with Dr. Molly left him feeling misunderstood and highly dissatisfied, causing him to limit the information he shared and to mistrust healthcare providers in general.

Dr. Molly’s treatment of Tik may have reflected implicit racial and heterosexist biases despite her own identification as a sexual minority (Table 1). Race/ethnicity factors prominently in perceptions of behavioral risk, personal responsibility, and culpability.^{49–51} Relative to Whites, patients of color are often provided with less information and time during visits, leading to lower engagement in SDM and visits that are characterized by less positive effect.^{52–54} White providers also tend to be more verbally dominant and less patient centered toward patients of color relative to White patients.⁵⁴

AAPI SGM face racism not only within larger society; racism within SGM spaces is well documented.^{27,55} Within gay popular media, racial stereotypes have depicted Asian gay men as sexually desirable insofar as they “fit” stereotypical roles of the submissive and passive lover.⁵⁶ Likewise, Black gay men have been stereotyped to be animalistic and

TABLE 3. CALL TO ACTION TO MITIGATE INSTITUTIONAL AND STRUCTURAL BARRIERS TO EFFECTIVE SHARED DECISION MAKING FOR ASIAN AMERICAN AND PACIFIC ISLANDER SEXUAL AND GENDER MINORITIES

<i>Call to action</i>	<i>Pertinent issues</i>	<i>Suggested actions</i>
Research	Aggregated data prevent analysis of critical AAPI ethnic differences and conflate AAPI subpopulations that vary by factors important to health (e.g., socioeconomic status, immigration status, language, and cultural beliefs).	Disaggregate AAPI demographic data in measurement and reporting. Collect ethnic subgroup data (e.g., Vietnamese, Cambodian, and Hmong). Include AAPI SGM in national data collection. Over-sample AAPI SGM to achieve sufficient sample size. Collect information on sexual orientation and gender identity in addition to race and ethnicity to allow intersectional research approaches. Create requests for applications and other research opportunities to study AAPI SGM health (e.g., culturally tailored patient-centered care; communication and shared decision making).
Policy	English nonproficient AAPI SGM and their families may have difficulty accessing healthcare and SGM resources. Culturally competent care of AAPI SGM patients is not a priority.	Solicit and distribute flyers and materials regarding SGM resources and information that are available in different AAPI languages. Increase access to medical interpreters. Collect disaggregated AAPI patient-level data by language and ethnicity. Include care of AAPI SGM as a performance metric for healthcare organizations. Evaluate cultural competency toward AAPI and other SGM of color. Assess performance metric for care of AAPI SGM (e.g., compare patient experience measures across different patient groups).
Community development	AAPI SGM can be marginalized by both SGM and AAPI communities.	Create AAPI SGM spaces and community groups. Develop community forums that discuss AAPI SGM specific needs. Increase funding for capacity building and technical assistance for community-based organizations serving AAPI SGM.
Education	Most health providers are not well prepared to serve AAPI SGM.	Cultural competency training for providers should include the needs of AAPI SGM. Train mental/behavioral health providers in providing culturally tailored approaches for AAPI SGM. Educate AAPI organizations about SGM health issues. Educate SGM organizations about caring for AAPI clients. Assure patients of confidentiality to encourage disclosure. Incorporate data from evaluation of cultural competency and other performance metrics in provider training.

virile, while Latino men are stereotypically hot tempered and lascivious.⁵⁷ These sexual roles within the gay male community have roots in racist stereotypes.^{58–60} While little data are available on AAPI trans individuals, AAPI SGM are often marginalized both by AAPI and by SGM communities, affecting their experiences inside and outside of the clinic.

Discussion

A myriad of factors affect SDM with AAPI SGM, including (1) intrapersonal factors such as stigma and minority status stress; (2) interpersonal factors such as verbal and nonverbal communication stemming from implicit and automatic biases; and (3) systemic factors such as clinic culture

and policies.^{48,61–63} Table 1 illustrates key intersectional issues that affect SDM between clinicians and AAPI SGM as follows: (1) AAPI SGM are diverse, and effective SDM addresses this diversity; (2) SGM stigma can be especially powerful in AAPI communities; and (3) AAPI SGM are subject to discrimination and stereotyping in both the AAPI and SGM communities, which can lead to reduced trust and engagement in clinical care.

Table 2 offers practical tips and resources for clinics and clinicians to incorporate into their practice with AAPI SGM.^{22–26,34,35,38–40,42–46} Interpersonal and structural prejudice or inappropriate care based on the patient’s race, ethnicity, gender identity and expression, and sexual orientation can alienate patients and result in poor outcomes.

Although the use of ethnicity and gender as visible proxies for behavior can be automatic,^{4,64} stereotypes about ethnicity, gender, and sexual orientation can be incorrect and stigmatizing; rather, clinical care must be individualized and appreciative of the intersectional effects of each individual's culture and background.⁶⁵ Ways to improve SDM with AAPI SGM range from simple recognition and awareness of implicit and automatic biases to more complex institutionalized changes to clinic culture and procedures.^{22–26,36,38–40,42–46,66,67} These changes include eliciting sexual orientation and gender identity in a culturally competent manner, and training providers and AAPI SGM to empower patients to expect competent care and to take appropriate actions if they do not receive it (Table 2).^{35,40}

Conclusion

Significant institutional and structural barriers impede SDM with AAPI SGM. However, these barriers can be mitigated through increased research, policy, community development, and education (Table 3). Research among AAPIs is limited by data that are omitted, aggregated, or extrapolated. Ethnicity, sexual orientation, and gender identity need to be disaggregated, collected and analyzed to aid in interventions to achieve health equity.³³ Policy interventions can improve access to information and care for limited English proficiency patients and can make care of AAPI SGM a higher priority for healthcare organizations.³³ Safe spaces for AAPI SGM can be created as part of community development. Care of AAPI SGM can be improved through better cultural competency training of clinicians and redesigning clinics and systems to provide personalized care to patients.^{37,68}

AAPI SGM remain at high risk for health disparities, but SDM offers a promising solution. We can improve SDM with AAPI SGM and, ultimately, health outcomes if we are aware of the richness and complexity of each individual patient, and make concerted efforts to address the personal and structural barriers impeding the best possible care.^{68–70}

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