



Development of a Conceptual Framework for Understanding Shared Decision making Among African-American LGBT Patients and their Clinicians

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BACKGROUND: Enhancing patient-centered care and shared decision making (SDM) has become a national priority as a means of engaging patients in their care, improving treatment adherence, and enhancing health outcomes. Relatively little is known about the healthcare experiences or shared decision making among racial/ethnic minorities who also identify as being LGBT. The purpose of this paper is to understand how race, sexual orientation and gender identity can simultaneously influence SDM among African-American LGBT persons, and to propose a model of SDM between such patients and their healthcare providers.

METHODS: We reviewed key constructs necessary for understanding SDM among African-American LGBT persons, which guided our systematic literature review. Eligible studies for the review included English-language studies of adults (≥ 19 y/o) in North America, with a focus on LGBT persons who were African-American/black (i.e., $> 50\%$ of the study population) or included sub-analyses by sexual orientation/gender identity and race. We searched PubMed, CINAHL, ProQuest Dissertations & Theses, PsycINFO, and Scopus databases using MESH terms and keywords related to shared decision making, communication quality (e.g., trust, bias), African-Americans, and LGBT persons. Additional references were identified by manual reviews of peer-reviewed journals' tables of contents and key papers' references.

RESULTS: We identified 2298 abstracts, three of which met the inclusion criteria. Of the included studies, one was cross-sectional and two were qualitative; one study involved transgender women (91 % minorities, 65 % of whom were African-Americans), and two involved African-American men who have sex with men (MSM). All of the studies focused on HIV infection. Sexual orientation and gender identity were patient-reported factors that negatively impacted patient/provider relationships and SDM. Engaging in SDM helped some patients overcome normative beliefs about clinical encounters. In this paper, we present a conceptual model for understanding SDM in African-American LGBT persons, wherein multiple systems of social stratification (e.g., race, gender,

sexual orientation) influence patient and provider perceptions, behaviors, and shared decision making.

DISCUSSION: Few studies exist that explore SDM among African-American LGBT persons, and no interventions were identified in our systematic review. Thus, we are unable to draw conclusions about the effect size of SDM among this population on health outcomes. Qualitative work suggests that race, sexual orientation and gender work collectively to enhance perceptions of discrimination and decrease SDM among African-American LGBT persons. More research is needed to obtain a comprehensive understanding of shared decision making and subsequent health outcomes among African-Americans along the entire spectrum of gender and sexual orientation.

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INTRODUCTION

The 2011 Institute of Medicine (IOM) Report *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for a Better Understanding* describes how LGBT persons are often marginalized within medical settings and at increased risk for health disparities.¹ Understanding how to promote patient-centered care and shared decision making (SDM), in general and among LGBT populations, has become a national priority.^{2–6} The IOM, American Medical Association (AMA), American College of Physicians (ACP) and Association of American Medical Colleges (AAMC) have all endorsed shared decision making between patients and physicians.^{3–6} In 2015, the ACP published a position paper on LGBT health disparities that called for increased physician understanding of how to provide patient-centered care for LGBT persons that addresses both environmental and social factors impacting mental and physical health.⁷

Despite the increasing priority of both shared decision making and LGBT health within the medical community, there has been little attention paid to “dual minorities”—LGBT persons who are also racial/ethnic minorities^{8,9}—despite their

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significantly increased risk for social disadvantage and poor health outcomes.^{10–13} Race, ethnicity, sexual orientation, and gender each represents a heterogeneous group of social identities (Table 1) that can interact *within* individual persons to magnify their risk for discrimination and poor health.^{14,15}

In this paper, we review key constructs necessary for understanding shared decision making among African-American LGBT persons, which guided our systematic literature review of SDM in this population. Together, these informed (and were informed by) the development of our conceptual model for understanding SDM in African-American LGBT persons. We report on the findings of our systematic review, present our conceptual model, and illuminate future research SDM directions for populations at the intersection of race and sexual orientation/gender.

Shared Decision making and Patient-Centered Care

Shared decision making, where patients and clinicians work collaboratively to identify treatment plans that meet patients' needs and preferences, is currently conceptualized as having three key domains: *information-sharing* between patients and providers, *deliberation* about the pros and cons of treatment

choices, and *decision making* about a treatment plan that is endorsed by both the patient and the clinician.^{16–20} Shared decision making, and patient/provider communication, has been associated with a number of positive health outcomes, including control of diabetes and hypertension, adherence to HIV antiretroviral therapy, improved mental health and well-being, and patient satisfaction.^{21–26}

Disparities in communication and shared decision making are well-documented among racial/ethnic minorities, particularly African-Americans,^{27–31} and there is growing research suggesting similar disparities among sexual and gender minority populations.^{32,33} These differences in patient/physician communication may be an important contributor to existing health disparities among marginalized populations.^{13,34} For African-Americans as well as LGBT persons, there is evidence that providers' unconscious racial and/or heterosexual biases can influence medical care and their expectations for patient adherence and SDM engagement.^{32–36} For example, one study revealed how physician perceptions about African-American men's likelihood of adherence to highly active antiretroviral therapy (HAART) influenced treatment recommendations, including the prescription rates for medications to prevent opportunistic infections.³⁶

LGBT persons, in general, may have identity-specific healthcare issues that put them at higher risk for poor health,

Table 1. Definitions and Terminology for Sexual Orientation, Gender Identity and African-American Race

Concept	Example Labels/Terms
Sexual Orientation Sexual orientation is often described as a continuum from exclusively heterosexual to exclusively homosexual, rather than distinct categories (e.g., homosexual, bisexual, heterosexual). Three components of sexual orientation: 1. Emotional and physical attraction to others of a particular sex 2. Self-reported identity (which may be concordant or discordant with attraction and sexual behavior) 3. Sexual behavior with male and/or female partners (which may differ from attraction and/or identity) All three components of sexual orientation can be fluid and change over the life-course	<ul style="list-style-type: none"> • Lesbian • Gay • Bisexual • Same-gender-loving • Queer • Straight or heterosexual • MSM (Men who have sex with men) • WSW (Women who have sex with women) • Sexual Minorities
Gender Identity A person's innate and inescapable perception of their own gender, which may, or may not, be consistent with the person's anatomical sex/sex assigned at birth. Some people perceive their gender as non-binary, or having aspects of both male and female gender. <ul style="list-style-type: none"> • Gender Expression—How we present to others might or might not align with gender identity Gender identity and expression can be fluid and change over the life-course.	<ul style="list-style-type: none"> • Transgender—An element of crossing-over or challenging binary gender roles or expectations. This may include: <ol style="list-style-type: none"> 1. People who identify and/or express their gender as opposite of their biologic birth sex 2. People who define themselves as a gender outside the either/or construct of male/female • Transsexual • Cross-dresser • Genderqueer • Androgyne • Bigender • Cisgender—a self-perceived gender that is consistent with sex assigned at birth. • Gender Minorities
Definition Ethnicity Affiliation with a cultural group and its practices, knowledge, history, etc. Color Skin complexion and tone Nationality Personal (and/or familial) citizenship Race and Racialization Social identity developed within systems of racial oppression and marginalization	African-American Context e.g., adaption of African, European and Native-American cultural traditions, intergenerational trauma from slavery and contemporary structural racism, Black cultural products in arts and humanities e.g., "dark skinned", "light skinned", e.g., United States citizenship, second-class citizenship e.g., racial stereotypes about promiscuity (e.g., hypersexual), physical ability (e.g., brutes, athletes, larger sexual organs), mental ability (e.g., underdeveloped, slow, hyperemotional), pain tolerance (e.g., higher threshold of pain), etc.

and for which patient-centered care and shared decision making may improve health outcomes. For example, there is evidence that transgender women may prioritize transition-related care, particularly hormone treatment, more so than primary care or HIV-related care,³⁷ and have fear of discriminatory treatment in the healthcare setting.^{38,39} The utilization of self-administered hormones (purchased from street markets) in unsafe doses³⁹ by transgender women could potentially be reduced by culturally tailored medical care that involves a shared approach to identifying health priorities and choosing treatment plans.³²

While there is growing literature about patient/provider relationships and SDM among racial/ethnic minorities and LGBT persons, little is known about these issues among populations that live at the *intersection* of such identities, such as African-American LGBT persons. Understanding how race, sexual orientation and gender identity can simultaneously influence shared decision making is an important step in addressing health disparities among such ‘dual minority’ populations.

Applying Intersectionality to Health Disparities

Health disparities research often focuses on a single social group (e.g., African-Americans, elderly populations, immigrants) while *adjusting* for other sociodemographic characteristics, rather than considering the interactive effects of multiple social identities. This can result in an incomplete understanding of how the cumulative lived experience of individuals contributes to health disparities, and accounts for some of the within-group variation noted among minority groups.^{40–42}

‘Intersectionality’ is the study of how multiple systems of social stratification (e.g., race, ethnicity, gender, sexual orientation) influence an individuals’ identity and lived experience, recognizing that every person holds a position (privilege or disadvantage) in different systems simultaneously, and that such positions can vary in magnitude and direction depending on time, place, and circumstance.^{43–46} For example, an African-American bisexual man may inhabit a different social position as a part of a community coalition to address HIV than while at work in the police department. Intersectionality also explores how different *levels* of a social framework influence individuals experiences, including the *intrapersonal* level (e.g., internalized racism),⁴⁷ the *interpersonal* level (e.g., bias, discrimination),⁴⁸ the *contextual level* (e.g., societal victimization such as hate crimes),⁴⁹ and the macro-level, where *structural inequalities* (e.g., education, income distribution) exist.¹²

Intersectionality highlights how persons with multiple disadvantages can have interactive effects on their health and well-being. For example, multiply disadvantaged persons are more likely to report interpersonal discrimination (conscious behavioral bias), microaggressions (*unconscious* behavioral bias), psychological distress, worse self-rated health, and more functional limitations than their singly disadvantaged or privileged counterparts.^{10,11,50–53} African-American LGBT

persons can be disadvantaged within multiple social systems, based on race, sexual orientation and/or gender.^{54–59} This multiple disadvantage may compel such persons to maintain several *separate* identities, in which they de-emphasize or conceal aspects of themselves in different communities as a coping mechanism to marginalization.^{12,14,59,60} For example, “code-switching” (behavioral adaptations to fit specific contexts)⁶¹ has been used by African-American bisexual men to avoid discrimination within the African-American heterosexual community.^{15,62} However, research suggests that having an integrated identity among African-American LGBT persons may be associated with higher levels of well-being and health promoting behaviors (e.g., higher self-esteem and life satisfaction, less internalized conflict and psychological distress, higher HIV prevention self-efficacy).¹⁴ Such persons who straddle separate groups, on the other hand, may have structural advantages as ‘brokers’ who can help diffuse behavioral changes and treatment innovations.⁶³

SYSTEMATIC REVIEW

Methods

We conducted a systematic review of the literature to identify articles on shared decision making (SDM) in the African-American LGBT population. PubMed, CINAHL, ProQuest Dissertations & Theses, PsycINFO, and Scopus were searched. The search strategy included MESH terms and keywords based on the following concepts: shared decision making (e.g., patient/provider communication, patient/provider relationship, shared decision making, participatory decision making, patient-centered communication, treatment decisions, decision aid, and patient empowerment, African-Americans (e.g., African-Americans, Blacks, minorities), LGBT persons (e.g., homosexual, lesbian, gay, bisexual, men who have sex with men, and transgender persons) (see Online Appendix 1). We also included MeSH terms and key words for concepts that were related to communication quality among minority populations such as trust, physician bias, and discrimination. Additional references were identified by hand searching relevant articles’ reference lists and the Table of Contents of key peer-reviewed journals.

We included studies written in English and did not limit studies based on the date of publication. We included all types of completed studies (i.e., qualitative studies, cross-sectional studies, observational studies, and clinical trials) that were conducted in North America (United States and/or Canada), included human (i.e., patient and/or physician) data, and included adults only (19 years old and above). We included studies that focused on LGBT persons who were African-American/black (i.e., >50 % of the study population) or included sub-analyses by sexual orientation/gender identity and race. We excluded studies on prevalence of behaviors (e.g., sexual practices, lifestyle behaviors) if there was no explicit relationship to patient/provider communication or SDM.

The results of the searches were combined and duplicates were removed. This process identified 2298 abstracts, which were independently reviewed by five of the co-authors to determine eligibility for study inclusion; disagreements were resolved by consensus. Data were abstracted from full text articles using an adapted abstraction form from Zaza and colleagues.⁶⁴ Thirty-eight studies were eligible for full text review; these were independently reviewed by the co-authors and discussed as a group. Ultimately, three studies met the inclusion criteria and an additional three were ‘near-misses’ that we include here to illustrate important issues in African-American LGBT SDM (Online Appendix 2). This systematic review adhered as closely as possible to the recommendations of the Preferred Reporting Items for systematic Reviews and Meta Analyses (PRISMA).⁶⁵

Results

Included Studies (Table 2).

Three studies met the systematic review’s criteria. One was a cross-sectional study and two were qualitative studies, one of which included a conceptual model of interaction between patients, providers and setting for African-American MSM. One study involved transgender women (91 % minorities, 65 % of whom were African-Americans), and two involved

African-American men who have sex with men (MSM). Sevelius et al. reported on antiretroviral adherence and healthcare experiences of transgender women and those of other HIV positive study participants.³² The study utilized an instrument to measure the quality of patient/provider interactions, which included items such as ‘feeling helped’ by the provider, receiving assistance with medication management (e.g., side effects), and feeling that the patient and provider had agreed on a treatment plan that the patient could follow (i.e., shared decision making). Transgender women reported significantly fewer positive interactions with their providers than non-transgender participants.³²

Wheeler conducted a qualitative study of African-American men who have sex with men (MSM) to understand the role of the patient/provider relationship in HIV/AIDS management.⁶⁶ He found that patients in the study reported that the patient/provider relationship impacted health beliefs (e.g., those with a collaborative [or ‘shared’] style were able to overcome patient normative beliefs that health encounters were traumatic occurrences) and medication adherence (e.g., clinicians were as a trusted source of information).⁶⁶ Because many participants had not disclosed their sexual orientation to those in their personal lives, the ability to do so with physicians placed a greater ‘premium’ on the patient/provider relationship. The ability to communicate in an

Table 2. African-American LGBT Shared Decision Making – Included Studies in Systematic Review

Reference	Study Objectives	Study Design	Population Characteristics	Results Summary	Shared Decision Making Element
Sevelius et al. ³²	Examine rates of self-reported antiretroviral adherence among transgender women and correlates of non-adherence, including patient perceptions of interactions with their providers.	Cross-sectional with comparison group. Interviews conducted.	HIV infected transgender women in San Francisco, Los Angeles, New York City and Milwaukee. Study group: 35 transgender women. 62.9 % were African-American. Comparison group: 2770 HIV-infected respondents on antiretrovirals. 47.9 % were African-American.	Transgender women were less likely to report adherence compared to non-transgender respondents. Transgender women reported fewer positive provider interactions compared to other HIV-infected individuals.	Addresses how often the respondent left a visit with the belief that she and her provider had agreed upon a treatment plan.
Wheeler ⁶⁶	Describe how patients and providers working together can improve HIV outcomes, including HIV prevention.	Semi-structured focus groups and individual interviews.	50 African-American MSM in New York City. 70 % gay identified. 30 % identified as non-gay, heterosexual or bisexual. 92 % HIV infected.	Patients voiced deriving support from providers who were firm in their recommendations. Provider interactions were particularly meaningful when they offered one of the only opportunities for patients to discuss their medical problems. Quality of communication in the patient-provider relationship affected the medical experience significantly. Black cultural competency was identified by patients as a desirable quality in their provider.	Addresses how the quality of patient-provider interactions influences the decisions made in HIV management and prevention.
Malebranche et al. ¹⁵	Explore the healthcare experiences, including barriers to care, communication with providers, and treatment adherence of African-American MSM. Examined the perceived influence of race and sexuality on healthcare experiences.	Qualitative study. Focus groups. Interviews consisted of open-ended questions.	81 participants, all of African descent and MSM in New York State and Atlanta. 53 % identified as gay.	Quality of communication in the patient-provider relationship affected the medical experience significantly. Black cultural competency was identified by patients as a desirable quality in their provider.	Describes factors that contribute to engagement with provider recommendations. Elicits information regarding communication between patient and provider.

open, honest manner, and to identify and respond to sociocultural cues about sexual orientation were reported as important facilitators of the patient/provider relationship.⁶⁶ Wheeler also presented a sociocultural model to describe the relationships between sociodemographic variables and health outcomes among African-American MSM.⁶⁶

Malebranche et al. conducted a qualitative study of African-American MSM to understand the social issues that influence barriers to medical care, communication with providers, and treatment adherence.¹⁵ The experiences of societal discrimination due to race (perceived as the dominant source of discrimination) and sexual orientation (particularly within the African-American community) were ones that: 1.) precipitated feelings of social isolation in both the mainstream gay community and the African-American community, 2.) promoted the development of a dual identity and ‘code-switching’ as a coping mechanism, and 3.) influenced expectations of providers within medical settings.¹⁵ Perceived discrimination, fear, and mistrust of healthcare systems fostered feelings of detachment from medical experiences, and served as barriers to provider communication and treatment adherence.¹² The quality of verbal communication was perceived as an important part of the patient/provider relationship and overall healthcare experience; it influenced the choice of clinic and satisfaction with care.¹⁵

Illustrative Examples (Table 3).

Several studies involved African-Americans and sexual minorities, but were excluded because these represented only a small subset of the study population, information on the intersectionality of participants was not included (e.g., race and sexual orientation demographics were analyzed separately), or because the nature of the study was about patient/provider relationships in general, and not specific to SDM. We discuss their themes briefly here because of their general salience to the systematic review. These studies found patient-reported disparities in communication (i.e., end-of-life care among patients with advanced AIDS) among racial/ethnic minorities (African-Americans and Latinos) and gay/bisexual men,⁶⁷ and fears of healthcare discrimination among transgender women of color that led to delays in seeking medical services.⁶⁸ Better physician/patient relationships, including higher measures of communication (general communication, HIV-specific information sharing, participatory decision making, and adherence dialogue), were positively associated with adherence to antiretroviral therapy.²⁰

CONCEPTUAL MODEL

The development of our model draws upon prior research and model development in two areas: shared decision making among African-Americans with diabetes^{19,69–71} and intersectionality among multiply disadvantaged groups.^{14,45,72–77} We also confirmed our conceptual model’s core constructs using the studies described in our systematic review.

The Environment

In our model, ‘the environment’ represents both physical (e.g., location, infrastructure, resources) and social (e.g., cultural, political) context in which people live, which shape their experiences and expectations, including service quality in health systems and interactions with physicians. We categorized the environment according to scope (society, community, and clinic), illustrated by concentric rings framing the SDM process. *Society* refers broadly to the structural and social systems within the U.S. (e.g., healthcare, housing), in which there exist pervasive inequities based on social position. The U.S. social system contains structural and social inequalities embedded in its normal operation. Although these inequalities are listed as “society”, they are pervasive throughout every level of the environment though potentially in different forms. *Communities* can be formed around multiple commonalities (e.g., religion, cultural practices) or identities (e.g., race, sexual orientation), and can transcend physical location (e.g., virtual communities). *Clinic* refers to the medical care setting in which the patient/physician encounter occurs. Clinic characteristics (e.g., ‘free’ clinic vs. private practice, affiliation with a medical school, primary care vs. subspecialty clinic [e.g., HIV/AIDS, oncology]) and geographic location may influence patient expectations about their quality of medical care, and affect their SDM self-efficacy.

Figure 1 offers a visual representation of an individual’s multiple axes of identity in separate systems of social stratification.⁷² Each axis is depicted as a ring that simultaneously intersects and interacts with every other axis.⁴⁵ The mirror represents how a person has internalized his/her social identities (e.g., an integrated identity vs. compartmentalized identities) and perceives him/herself in the world, as informed by his/her lived experiences.^{14,45,74} Thus, the mirror also represents the influence of society’s attitudes on an individual’s self-perception.

Figure 2 illustrates how patients and providers perceive each other, based on their known or assumed roles and social identities. All perception is influenced by generalized and oversimplified ideas (stereotypes) and preferences (prejudices) that affect people’s attitudes, actions, decisions and understandings of others (implicit biases).^{75–77} Figure 2 depicts how patients and providers, given their lived experiences, bring their own expectations of one another to the clinical encounter, which can affect patient/provider communication and behaviors. Figure 2 also illustrates the influence of society’s expectations about how patients and physicians should behave given their roles and social identities. These societal beliefs may affect the way patients and providers perceive and communicate with each other during the clinical encounter.

Figure 3 builds upon Peek et al.’s conceptual model of how race as a social identity impacts shared decision making, behaviors and health outcomes.⁷¹ We expand this model to include multiple other social identities (e.g., gender, sexual orientation) and how these identities intersect with each other.

Table 3. African-American LGBT Shared Decision Making – Illustrative Examples

Reference	Study Objectives	Study Design	Population Characteristics	Results Summary	What's missing
Bith-Melander et al. ⁶⁸	Examine the needs of transgender ethnic minorities and explore attitudes towards healthcare in this population.	Ethnographic qualitative study. Focus groups and in-depth interviews with youth and adults.	Transgender youth and adults of color in San Francisco. Group included Asian/Pacific Islander, African-American and Latino(a) individuals. 8 African-American individuals (7 youth, 1 adult) participated in the focus groups. 6 African-American individuals (4 youth, 2 adults) participated in the in-depth interviews.	Individuals described concerns that healthcare providers may not be culturally competent, which resulted in waiting to obtain healthcare until it was critical. The Latino (a) group noted that healthcare providers were not versed in the needs of transgender individuals.	Lacks discussion on specific patient-provider interaction and shared decisions. Does not focus on African-American adults since the majority of participants are youth.
Curtis et al. ⁶⁷	Explore end of life discussions between providers and patients with advanced HIV, and the characteristics of participants.	Prospective cohort study. Structured in-person interviews were conducted with patients. Telephone interviews were conducted with practitioners.	57 patients with AIDS and their primary care clinicians in Seattle. Patients were recruited from community-based organizations, university and private clinics and an AIDS research clinic. Practitioners were recruited from community and university settings. 16 % of patients were African-American. 65 % identified as gay or bisexual.	African-American patients were less likely to report engaging in discussions on end of life care. Gay or bisexual men were more likely to have discussed end of life care than men who were drug injectors or women with high-risk sex partners.	Includes both African-American and gay or bisexual participants but no data on intersectionality between these two groups.
Schneider et al. ²⁰	Examine the interaction between patient/physician relationship and rate of adherence to antiretroviral therapy for patients with HIV.	Cross-sectional analysis. Adherence was measured by a 4-item self-report scale. Physician-patient relationship was assessed using several scales, including participatory decision making.	554 participants with HIV on antiretroviral medication from 22 outpatient HIV practices in the Boston area. 14.5 % were African-American. 57.4 % were MSM.	Adherence was significantly and independently associated with general communication, HIV-specific information, overall physician satisfaction, willingness to recommend, trust and adherence dialogue.	Intersectionality between race and gender identity and/or sexual orientation not explicated.

In Peek's model, the ability for patients and physicians to engage in shared decision making with each other is determined by their individual decision making preferences, trust in each other, and the existing patient/physician relationship. We have added arrows to show the important interactions between preferences, trust and the patient/physician relationship in shaping the SDM experience. In Peek's model, self-efficacy, understanding, trust and satisfaction are downstream patient outcomes that mediate patient self-management behaviors and subsequent health outcomes. In our conceptual model, we have expanded these downstream effects to include physician outcomes (e.g., increased job satisfaction, increased physician self-efficacy and understanding in caring for patients who are racial, sexual and/or gender minorities) that improve care delivery to the patient population and contribute to improved patient health outcomes.

While we represent the conceptual model in three different figures (described above), it is important to note the inter-relationships and bidirectional influences between each figure, especially how social identity (Fig. 1) and perceptions of others (Fig. 2) can directly influence shared decision making (Fig. 3). Figure 4 combines all three figures into a single image to underscore these complex inter-relationships. For example, in response to perceptions or expectations of racism or heterosexism by physicians (Fig. 2), patients may withhold information (e.g., sexual orientation and sexual practices) or alter their behaviors (e.g., "code-switching" by African-Americans to adopt a more deferential tone to white physicians) in attempt to influence provider perceptions and ensure a higher quality medical care. Such "impression management" behaviors are commonly utilized strategies among marginalized populations, and can impact the patient/physician relationship and SDM.^{15,61,62}

Identity & Self Perception

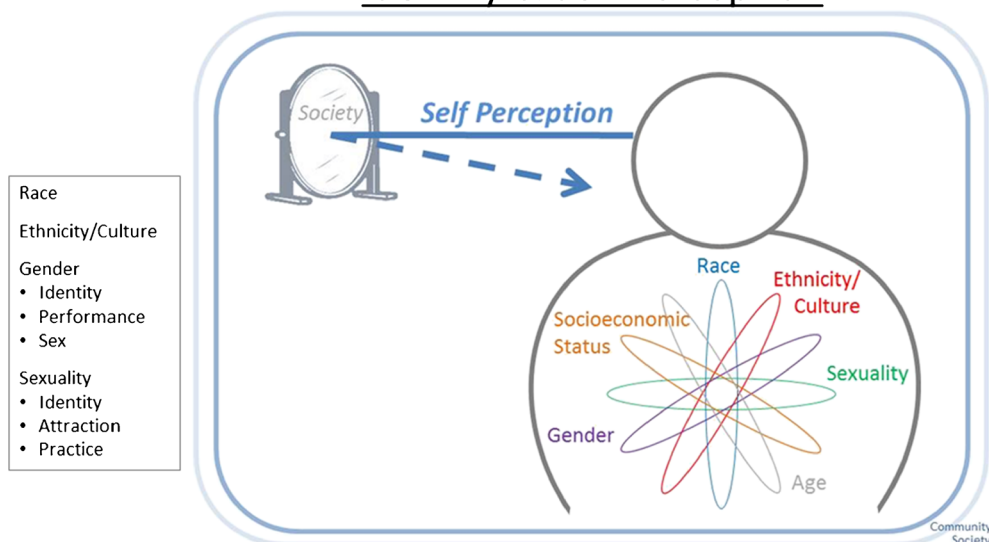


Figure 1. Identity and self-perception.

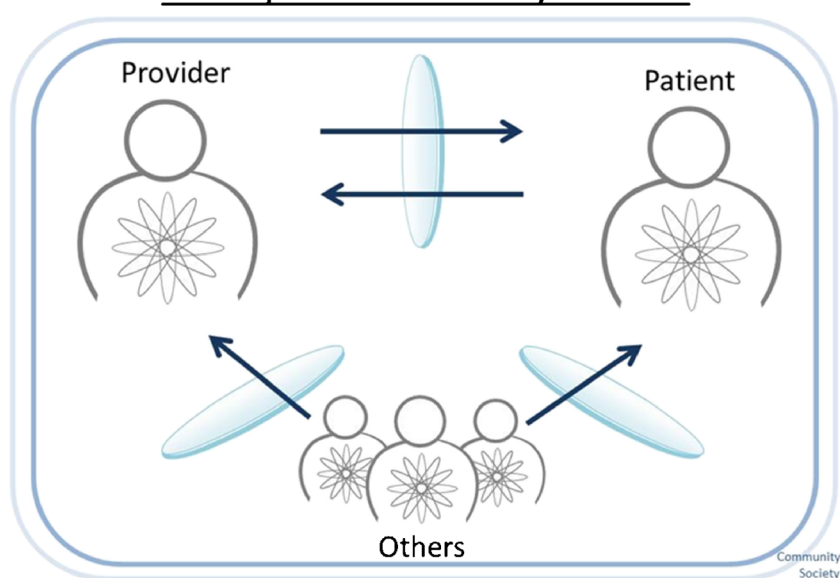
DISCUSSION

This paper underscores the importance of helping physicians to understand the multiple, intersecting social identities that African-American LGBT persons have and how these intersections shape lived experiences. These experiences are complex and not easily made explicit within a SDM context. African-American LGBT persons are thus at potential increased risk for discrimination, marginalization, and worse mental and physical health outcomes. African-American LGBT persons may live in a compartmentalized (vs. integrated) manner, which also may contribute to worse mental and

physical health outcomes. Thus, creating a safe space for African-Americans who are LGBT to engage all dimensions of their identities may facilitate better patient/provider relationships, communication, and treatment adherence among this population—all necessary components of SDM.

In this paper, we also describe a conceptual model, informed by previous work,^{14,19,45,69–77} that demonstrates how social identity, perceptions of social identity, and structural inequities all inform shared decision making between patients and physicians. Expectations for, and the interpretation of, clinical encounters are often influenced by past experiences and normative beliefs about physicians and healthcare deliv-

Perception of and by Others



Lenses include: stereotypes, prejudices, and implicit biases, and normative beliefs

Figure 2. Perception of and by others.

Shared Decision Making Process

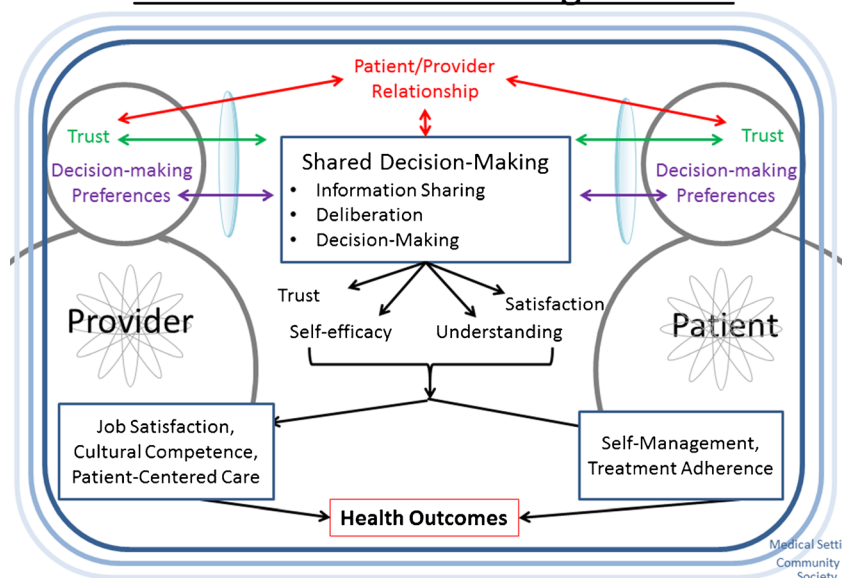


Figure 3. Shared decision making process.

ery.¹² For example, prior experiences with discrimination, based upon racialized encounters, may influence how willing patients may be to fully disclose sexual orientation for fear of additional discrimination.

Shared decision making, in its original conceptualization, assumes that all patients can understand the options available to them (if properly informed) and have similar self-efficacy and skills in choosing and implementing treatment plans.^{16,17} However, persistent structural inequities and social advantage/disadvantage promote learned helplessness⁷⁸ and entitlement/privilege⁷⁹ among populations in ways that encourage some patients to believe they have fewer options and lower self-efficacy, and encourage others to believe they have more options and higher self-efficacy, regardless of the external realities. Structural inequality affects not only the material realities (e.g., proportion of goods and services available) of a person's life, but also the internal beliefs and expectations that may obscure perceptions of those material realities. That is, persons with multiple social disadvantages may not only have less access to medical care and limited treatment options given to them, but they may also perceive that they have *even fewer* options than they actually do. Thus, fully engaging African-American LGBT persons in shared decision making requires that physicians and health systems work to create equal, trusting relationships with patients and also ensure equal access to treatment options and medical care.^{13,69,80–82}

It is important to note that *both* physicians and patients are impacted by the relative privilege and disadvantage associated with multiple systems of social stratification. The healthcare setting is a structural system in which there is a hierarchy of power/advantage based on roles (e.g., physician vs. clerical staff, physician vs. patient) as well as social identities (e.g., race, gender, sexual orientation). Thus, the power dynamics between

physicians and patients are not the same in every patient/provider relationship. Future research should explore how *physicians* who are African-American LGBT persons may impact SDM with patients of similar and different identities.

Our systematic review identified only six relevant studies to better understanding SDM among African-American LGBT persons, which reflects the general paucity of literature about the health of persons at the intersection of race/ethnicity and sexual orientation/gender identity. All of the studies focused on HIV infection and none dealt with African-American women who were sexual minorities or African-American transgender men. While research indicates that decision-aids can improve shared decision making among racial/ethnic minorities,⁸³ none of our studies identified clinical tools such as decision aids to assist in SDM among African-American LGBT persons. And although concerns about healthcare discrimination and other organizational factors (e.g., loss of privacy) were noted themes, we did not find any organizational or clinician *interventions* to improve SDM among this population. This is particularly concerning given the array of clinical contextual factors that can be leveraged to support SDM.⁸⁴ Thus, much more research is needed to obtain a comprehensive understanding of shared decision making among African-Americans along the entire spectrum of gender and sexual orientation, and how patients' *intersectionality* can influence physician perceptions and behaviors, the patient/physician relationship, and shared decision making within the clinical encounter.

This paper focused on the synergistic negativity that multiple minority statuses may engender. Less is known about how having an African-American LGBT status can lead to social *advantages*, and subsequently *improved* health outcomes. Dual statuses are common among those who are “bridges” or brokers within their social networks.⁶³ Such persons may have

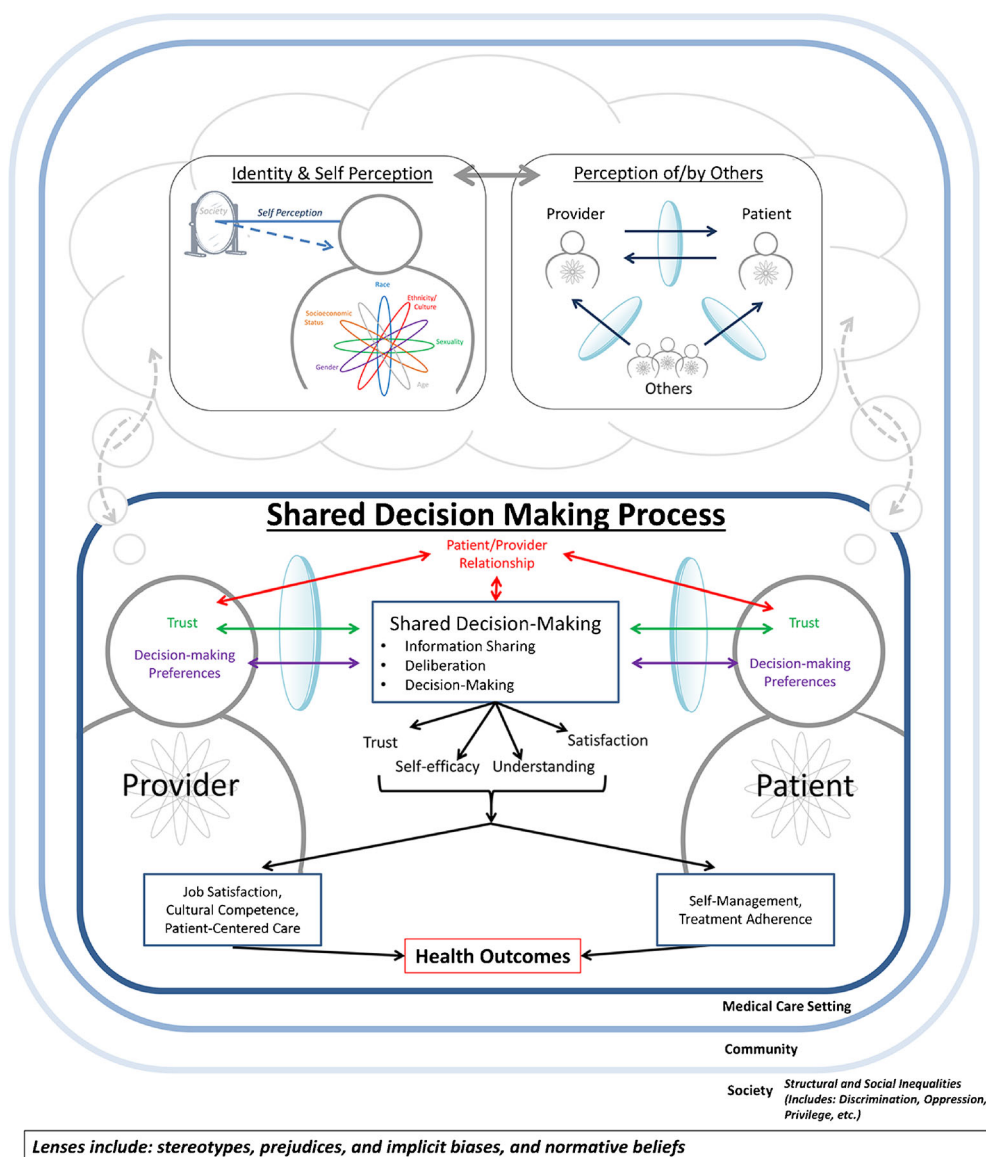


Figure 4. Conceptual model of shared decision making among LGBT African-Americans.

access to information that is helpful to both physicians (e.g., normative cultural beliefs, patient populations) and patients (e.g., new medical treatments) that make them effective change agents and bridges between health systems and marginalized populations.⁸⁵ Additional research is needed to better understand how African-American LGBT persons, and other ‘dual minorities,’ can be leveraged to improve health behaviors, physician skills, shared decision making, and health outcomes among these populations.

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