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Factors Associated with Shared Role in Making Decisions about Antiretroviral Treatment:
An Analysis of Data from Project IN-CARE

By

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Degree to be awarded: Master of Public Health

Epidemiology

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Ashley Loomis

B.A. St. Olaf College, 2010

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An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
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Abstract

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Results: Among clients included in the data for analysis, eighty-three percent reported joint decision-making, 10% relied on their provider, and 8% made most or all of the decisions themselves. Black or African American men, men who were over the age of 40, and clients who reported higher disagreement with statements about the provider making decisions about a patient's health, were independently more likely play a passive role in decision-making. Clients who made decisions themselves expressed greater distrust in the general use of medications.

Conclusions: These findings may be used to create environments that foster positive patient-provider relationships through empowering older and African American patients to engage more in their appointments and dispelling myths about treatment. Further studies investigating effects by demographic characteristics such as age, race/ethnicity, and level education are recommended.

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CHAPTER 1: LITERATURE REVIEW

With its first appearance in the United States over 30 years ago, human immunodeficiency virus (HIV) was initially a deadly and terrifying disease. According to the Centers for Disease Control and Prevention (CDC), approximately 1,148,00 people in America are infected with HIV as of 2009 (1). While a cure has yet to be discovered, treatment is highly effective, not only in controlling the illness, but also in reducing risk of transmission. Education, counseling, and condom use are effective and accepted methods of preventing the spread of HIV (2). Technology has made great strides in the development of accurate and rapid testing, yet around 18.1% of people living with HIV in the U.S. are unaware of their status. In addition, although overall incidence has been stable in recent years years, it is rising in some subpopulations, including young adults and men who have sex with men (MSM) (1). Similarly to trends nationwide, HIV prevalence in MSM living in Chicago, Illinois has also increased, from 18.1% in 2008 to 20.9% in 2011, with the greatest increases occurring among white and black men (2).

Many barriers to preventing and treating HIV affect MSM, not limited to stigma, lack of education surrounding transmission and prevention, cost of and access to testing and treatment, and adherence to treatment (1). Several of these barriers may also affect MSM who are living with HIV, especially MSM of color. For example, 33% of HIV-infected black and 21% of HIV-infected Hispanic MSM in Chicago were unaware of their HIV status (2). While these numbers still show a significant number of undiagnosed infections, they do represent a substantial decrease since last evaluated in 2008. This may be due to community-wide interventions in testing. However, becoming aware of one's HIV status is one of the

barriers to overcome among people living with HIV. Linkage and access to care is another complex issue affected by many factors (2).

Linkage and Retention in Care

Engaging people living with HIV in care and creating an environment conducive to helping them stay in care is important in maintaining a healthy and productive life for the individual. Yet many obstacles may prevent this successful linkage and retention in care. Stigma around the HIV infection may avert people from getting tested in the first place (3). One must be aware of their status to even begin to seek care. MSM may encounter additional stigma due to homophobia and discrimination from peers, family, or healthcare providers (4, 5).

One study that consisted of five focus groups conducted around the country found both physical and social barriers to engagement in care for people living with HIV(6). Physical obstacles included lack of funds, insurance, transportation, and housing. Unwillingness to accept HIV status, and having distrust and skepticism surrounding health care constituted the social and health-belief related barriers (6). Skepticism was also present in other studies, particularly surrounding racial disparities in care. African Americans were more likely to show distrust in general information surrounding HIV, in treatment, and in their providers (7, 8). Racial/ethnic concordance may influence trust in the healthcare system as well; patients who were of the same race or ethnicity of their providers did not report any disparity in trust of the provider, but reported a lower degree of mistrust in the system (9).

Initiation of and adherence to HIV treatment is yet another important aspect of care. With the introduction of highly active retroviral therapy in 1996, progression to and deaths due to acquired immunodeficiency syndrome (AIDS) have decreased substantially (10).

Adherence to antiretroviral treatment (ART) is important to persons living with HIV to not only maintain health, but also decrease likelihood of transmission to a partner. Just within the past few years, a clinical study (HPTN 052) among mostly serodiscordant heterosexual couples showed a 96% risk reduction of transmission among those couples where the HIV-positive partner initiated treatment early as opposed to delaying treatment (11). While this study may have limits in generalization to other populations, its findings were nonetheless monumental, and strengthened the indication that treatment could be used, along with other methods, to help prevent HIV.

Although the benefits of treatment are without question, many issues may pose inhibit people living with HIV from initiating ART and maintaining optimal adherence to the medications. Since drug resistance is more likely to occur in patients who do not achieve near perfect adherence to their treatment, strict adherence is critical. Not only does resistance decrease effectiveness of the treatment for the person taking it, but the resistant strain could be transmitted to another person and limit their treatment options as well (5). These barriers to care occur both on the individual and structural level. Individual level factors that may cause instability in daily life and may inhibit people from engaging in care after diagnosis with HIV include substance abuse, incarceration, mental health issues, having previous negative experiences with medical care providers, feeling healthy, and difficulties in coping and accepting HIV status (12). Structural level factors may include cost of care, transportation, unemployment, homelessness or housing instability, and stigma (13).

Those who have overcome these barriers and have initiated ART often still face obstacles in their care. Perfect, or near complete adherence to treatment, is important in maintaining health and preventing resistance to the drugs. Many of the same factors that block people infected with HIV from seeking care in the first place inhibit optimal treatment

adherence as well. In addition, inadequate health insurance, lack of social support, skepticism surrounding the importance of treatment, and being younger have also been found to be associated with poorer adherence (6, 12, 14, 15).

The Patient-Provider Relationship

Among many factors that lead to good outcomes in HIV care, the patient-provider relationship is becoming better recognized as a factor that may promote progress towards improved health. Over the years, this relationship has been moving away from one where the provider makes all of the medical decisions for the patient (16). Now, as increasing research has shown, patients are encouraged to participate more in appointments with their doctors regarding decisions about their health and care (17). Studies investigating factors affecting ART adherence, viral load, and other HIV-related matters commonly find that patients have better outcomes when they make the decisions about treatment or other HIV-related health decisions with their providers, as opposed to making them alone or having the provider make the majority of decisions. In a qualitative study of patients who achieved 100% adherence, it was found that having an ongoing relationship and feeling supported by the physician and staff were commonalities amongst these patients (18). Additionally, trust in one's provider has shown correlation with a higher use of health care and preventative care, greater contentment with health care services, and better medication adherence. However, this trust may differ by race; African Americans have reported a lower level of trust in their providers, in addition to a greater amount of skepticism surrounding HIV infection and treatment (7, 8).

Treatment scheduling may be complicated and some patients may experience side effects and toxicity, although drug improvements in recent years have made taking treatment

easier by lessening side effects and simplifying regimes; research for improvement in this area continues. Patients have also reported confusion regarding physician's directions, and forgetting to take the medication or changing the dosing schedule because of side effects, and not wanting to take treatment in public (5, 19). Chesney et al. also suggests that improving the patient-provider relationship through provider communication and counseling on adherence may help with patients who have difficulties with the dosing schedule, side effects, or other drug-specific complications (19).

A study conducted in 1989 by Brody et al. on adults with minor illnesses (HIV was not addressed) was one of the first to investigate the characteristics of the relationship between a patient and provider with regards to roles in decision-making about the patients' health and care and the effect on general health outcomes. This sample consisted only of adults with minor illnesses; 44% preferred to share the decision-making with their provider. While the researchers did not find differences with regards to age, sex, insurance status, or provider's perception of the patient's illness, they did find that participants who were more active in decision-making (made most of decisions or shared decision-making with provider) as opposed to those who were passive and let the provider make most or all of the decisions reported a perceived improvement of symptoms of their acute illnesses one week after the appointment with their doctor (20).

Other studies investigating patient-provider relationships have also shown that a higher level of patient involvement is associated with several positive health outcomes. Findings not limited to people living with HIV show that a greater patient involvement was associated with better control over and perceived improvement in illness, better overall quality of life, fewer and shorter hospitalizations, and better satisfaction with their doctors (17). Engaging patients through communication during appointments is beneficial to the

patient's health. However, racial disparities exist in this aspect of the relationship. One study found that black patients spoke less than the white patients during visits with their HIV providers (21). While reasons for this disparity is not entirely clear, the authors recommend interventions to empower and coach black patients and encourage providers to ask more questions during appointments to engage in greater communication (21). In addition to a higher level of communication and other forms of active engagement during appointments, preferring to have joint decision-making around HIV treatment is associated with better outcomes as well (17).

While much research has shown the benefits of engagement in decision-making, and while medical practice is moving in this direction, patients may still not be sharing at the level at which they desire. Using the five-level Control Preferences Scale created by Denger et al. (as cited by 16), one study measured both the desired and perceived role in making decisions about treatment and found that nearly 60% of the patients wanted to share in control with their providers, but over half reported that they were not able to do this in their last appointment where they discussed ART with their provider (16). This disconnect is concerning for progress in improving the patient-provider relationship and fostering an environment for achieving high levels of HIV treatment adherence. It is clear that what happens during the appointments and what factors in a patient's life may shape control and decision-making call for further investigation.

Now that the benefits of a collaborative patient-provider relationship have been established, the next step is to investigate what factors may enable a productive and positive relationship. While in-depth research regarding associations between social determinants of health and engagement in decision-making has not been conducted, basic qualitative and quantitative investigations have been explored. The study cited earlier that found a disparity

between actual and preferred control also found that patients who chose not to initiate ART frequently mentioned that although they wanted their physicians to make decisions about treatment with them, they made the decisions themselves because they feared a lack of support from their physician (16).

To measure engagement with a provider, Bakken et al. used a 13-item scale that included items such as the degree to which the provider respects the client, listens to the client, and supports the client's decisions (22). They found a negative association between levels of engagement and having injected drugs, but did not find any relationship with gender, age, or race of patient. However, they do mention that this conflicts with other studies' findings, possibly due to their use of convenience sampling, and cite other studies that find associations with gender, race, and age (22). Aharony et al. found that those who have greater satisfaction with their relationship with their provider are more likely to be older or female (23). Ross et al. found that satisfaction in interpersonal aspects of the relationship were older, and had lower income, education, and employment (24). While they did not find correlations between satisfaction and demographic characteristics of the patient, Bakken et al. did find that clients who had better mental and general health perceptions in regards to quality of life reported greater engagement with their providers (22).

As illustrated above, many studies have described the benefits of a positive patient-provider relationship. However, the association between social and demographic factors and the patient-provider relationship remains largely unexplored. Since shared decision-making has been previously shown to produce the best outcomes for the patient, especially in terms of ART adherence, a logical next step would be to explore the factors and characteristics that are associated with shared decision-making in order to inform not only providers, but also public health HIV interventions.

CHAPTER 2: MANUSCRIPT

Abstract

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Conclusions: These findings may be used to create environments that foster positive patient-provider relationships through empowering older and African American patients to engage more in their appointments and dispelling myths about treatment. Further studies investigating effects by demographic characteristics such as age, race/ethnicity, and level education are recommended.

Introduction

Nationwide, human immunodeficiency virus (HIV) has declined in the general population, but has increased in some subpopulations, including young adults and men who have sex with men (MSM) (1). Similarly to trends nationwide, HIV prevalence in MSM living in Chicago, Illinois has also increased, from 18.1% in 2008 to 20.9% in 2011, with the greatest increases occurring among white and black men (2). Despite the increase in prevalence, there have been hopeful improvements in other areas. From 2008 to 2011, the proportion of MSM in Chicago who did not know their HIV status decreased from half to under a quarter. In addition, the percentage of HIV positive MSM on antiretroviral therapy rose over that time period, especially among minority MSM: Black men experienced an increase from 44% to 88% and Hispanic men saw a growth from 50% to 82%. In contrast, 90% of white men were already on treatment in 2008, and by 2011, that proportion was at 100% (2).

Research and interventions surrounding linkage to and retention in care, including treatment uptake and adherence, has historically focused on individual-level factors, but is expanding to include system-level determinants as well. Engaging in and staying in care may be influenced by lack of funds, insurance, transportation, and housing, unwillingness to accept HIV status, and having distrust and skepticism surrounding health care (6). Barriers to ART adherence also include treatment-specific factors, such as complexity of dosing schedule, side effects, and skepticism surrounding the importance of treatment (5, 19, 8). Younger age, homelessness, a history of substance abuse or mental health issues, experiencing HIV stigma and low social support, and poor patient-provider relationships are also considerations (5, 6, 12, 13, 14, 15).

Engagement in the patient-provider relationship through balanced decisional roles has shown to be one of many important influences in adherence to treatment. Both preferring to share and experiencing shared decision-making with providers is associated with better outcomes in HIV such as better HAART adherence and having an undetectable viral load (17). However, this level of engagement may not be occurring to the extent that patients desire (16). In order to foster an environment for achieving better outcomes in HIV, more research is needed to investigate the characteristics associated with passive and active engagement during visits with an HIV provider. We seek to investigate which demographic and social factors are associated with a client sharing HIV treatment decision-making with his provider.

Methods

Project IN-CARE

IN-CARE is a three-year project in its third year funded by AIDS United, and is being implemented by the AIDS Foundation of Chicago with consultation from researchers at the San Francisco Center for AIDS Prevention Services. Intervention takes place at three AIDS service organizations in Chicago, Illinois. The purpose of Project IN-CARE (Identify, Navigate, Connect, Access, Retain, Evaluate) is to evaluate and improve access and linkage to care for HIV positive men in Chicago through a peer health navigation program. It is a longitudinal study, following clients over an 18-month period, with the follow-ups occurring every 6 months. As of August 2012, enrollment is currently ongoing.

Data Collection and Study Participants

Potential clients for IN-CARE were initially recruited from four clinics in Chicago. They were eligible if they were at least 18 years old, male, HIV positive, have sex only with men, mostly with men, or sometimes with men, and either newly diagnosed with HIV or previously diagnosed but not currently in care. At the start of IN-CARE, only MSM of color were recruited; however, after the first year, eligibility criteria changed and men of any race/ethnicity were eligible to participate. The baseline survey consisted of a face-to-face interview and a written survey, each lasting around 20-30 minutes. Clients also participate in follow-up surveys at 6, 12, and 18 months.

The face-to-face interviews, self-administered questionnaires, and telephone surveys contained questions about treatment adherence, medical decision-making, status disclosure, social support, alcohol and drug use, mental health, barriers to appointment keeping, general health status and other health needs, beliefs about HIV medication, history of trauma, gay-related harassment, internalized heterosexism, and HIV-related stigma. Demographic information such as age, race, education, and housing status was also collected. The measurement instruments on the surveys were adapted from previously validated assessments.

Measurement of Data

The AIDS Foundation of Chicago completed appropriate informed consent with all eligible and willing clients and secured Institutional Review Board (IRB) approval from the partner agencies that required IRB approval. The Emory University IRB approved this study as a secondary analysis. Enrollment in IN-CARE is still ongoing, but the dataset for use in this thesis only contains data collected from June 2010 through August 2012.

The original dataset contained 584 participants. The men recruited for IN-CARE did not have to ever have had an appointment with an HIV provider; however, some of the clients still answered the question about shared decision-making about treatment in an HIV appointment even if they did not report having an appointment at some point in their history. Therefore, we restricted the analysis to men who either noted in the eligibility form that they had at least one appointment with an HIV provider in the past twelve months, or had given the year in which they had their last appointment. This eliminated 232 participants. We also removed all 21 clients who did not answer the question about who makes the decision about HIV treatment, bringing the number of participants for analysis to 331.

The dependent variable in this analysis was measured using a single item adapted from Beach et al. about roles in decision-making (17). Clients were asked how decisions about HIV treatment were made during appointments with their HIV provider, and could choose one of three options: "I make most or all of the decisions," "My provider and I make the decisions together," or "My provider makes most or all of the decisions."

We included three scales as independent variables in our analysis: The short version of the Social Provisions Scale (SPS) (25, 26), which has 12 items, the Autonomy Preference Index (API) (27), which has 6 items, and Beliefs About Medication Questionnaire (BMQ) (28), which has 8 items. See Appendix A for all items in the scales. The SPS assessed the client's level of social support from friends, peers, coworkers, etc, the API included statements regarding the client taking an passive role in decisions about general health and letting the provider make decisions in a variety of situations, and the BMQ assessed the client's position on the general use of medications. The scales require the clients to rate each statement as "Strongly agree," "Agree," "Neither agree nor disagree," "Disagree," or "Strongly disagree." Individual items were reverse-coded where appropriate so that they

were all in the same direction within each scale. To determine whether it would be appropriate to combine the items into a single variable for their respective scales, we calculated Cronbach's Alpha for each scale. Upon finding that the alphas were adequate (alpha = 0.905, 0.701, 0.839 for the SPS, API, and BMQ, respectively) we summed each scale. We then tested each of these three new variables, along with the continuous age variable, for normality by comparing histograms and normality statistics. In addition, we looked at plots for each of these variables, by level of decision-making, where shared decision was the reference level. Age was the only variable that needed adjustment; we dichotomized the variable at age 40. Finding that the rest of the continuous variables satisfied normality assumptions, we did not perform any transformations on them.

Additional categorical variables were redefined or had levels combined due to low cell counts or for simplification. The question on the baseline survey originally included the categories "White", "Black or African American", "Asian Indian or Alaska Native", "Asian", and "Native Hawaiian or Other Pacific Islander". However, due to low counts in several of the races, the variable was redefined by combining the last three categories into one: "Other". Clients were also asked a single item about the extent to which they felt their provider knew them as a person (29), and were given the same five options as in the three scales.

Highest level of education completed, with four options, was also measured but did not need to be adjusted. For all questions, clients were given the option to refuse to answer items or skip sections; thus not every question contains data for every client.

Description of Analyses

Exploratory data analyses measured associations between the dependent variable and independent variables. Pearson chi-squared statistics were used for variables where data were not sparse, and Fischer's Exact tests were used for the majority of the categorical variables, since many had low frequencies in some of their levels. The degree of missing data for independent measures and potential impact on the dependent variable was also analyzed but no significant effects were identified and imputation was not used.

For bivariate analyses of categorical variables, logistic regressions were used to analyze shared decision-making for HIV treatment. Two variants of binary regressions were conducted: One compared clients who made the decisions themselves with clients who shared the decision-making, and another compared clients who experienced having the provider make all the decisions with shared decision-making. Primary analyses of the scales were conducted using the Wilcoxon rank sum test. To assess presence of confounding, we used these binary logistic regressions (keeping shared decision-making as the referent level) to calculate adjusted and unadjusted odds ratios and 95% confidence intervals for each scale. For these multivariate analyses, we built six models in total: one for each scale adjusting for age in provider-led decisions, and one for each scale adjusting for age in client-led decisions. Due to low cell counts in level of education, race, and ethnicity, we were only able to adjust for age. To test the goodness-of-fit for the adjusted models, we used the Hosmer-Lemeshow test. For all analyses, significance was determined using a two-sided p-value at the 0.05 level.

All analyses were conducted using statistical software SAS version 9.3 for Windows (SAS Institute Inc., Cary NC).

Results

Characteristics of the Study Sample

Table 1 summarizes the demographic characteristics and other covariates of interest of the 331 clients enrolled in IN-CARE that were included for analysis. The mean age of the clients was 38, and a majority of the clients were black or African American. Most of the clients had a high school diploma or higher, 15% had not completed high school, and 18% had a college degree. A vast majority of clients reported sharing decision-making about HIV treatment with their providers (82%), as opposed to the client making most or all of the decisions (8%) or the provider making most of all of the decisions (10%).

Bivariate analyses: I make most or all of the decisions

None of the levels of race, ethnicity, education, or age were significantly associated with the client making decisions about treatment (Table 2). Additionally, none of the levels of agreement as to whether or not the client felt the provider knew him as a person were statistically significant. The only scale that was significant in the Wilcoxon rank sum analysis was the BMQ, where clients who made the decisions themselves reported lower scores (median 24.0, IQR 11.0), meaning that they displayed a greater degree of skepticism about general use of medications than those who shared with their provider in the process (median 29.5, IQR 7.0) (Table 2). All three of the scales were statistically significant in binary logistic regressions, but with small effect sizes (Table 3). The SPS scale showed an 8%increase in odds of the client-led decision-making for every one-point increase in total agreement with statements about low social support. Similarly, one-point increases in disagreement with statements along the lines of provider control over decisions about a patient's health (the

API), odds increased by 1.10. Finally, for the BMQ, clients were less likely (OR = 0.89) to make most or all of the decisions themselves with every one-point increase in disagreement with items portraying the prescription or use of medications for general purposes as harmful or unnecessary.

Bivariate analyses: My provider makes most or all of the decisions

Race and age were found to have statistical significance when comparing clients who reported passive decision-making to joint decision-making about treatment (Table 2). Compared to white clients, Black or African American clients were 3.6 times more likely to report having the provider make decisions about treatment than experiencing joint decision-making. Clients 41 and older were more likely to have their provider make most or all of their decisions than share in decision-making, with an odds ratio of 2.40 (95% CI 1.07, 5.70, $p = 0.03$). None of the levels of agreement for the client feeling his provider knows him as a person were associated with the outcome. In both binary logistic regressions and Wilcoxon rank sum tests, the API was the only scale significantly associated with the decision-making about treatment being led by the provider. The median API score for provider-led decision-making was lower (14.0, IQR 8.0) than that of a collaborative role (17.0, IQR 6.0), so those who experienced passive decision-making agreed to a greater extent that the provider should take the lead in making decisions about a patient's health (Table 2). Negatively associated with the provider making decisions, the odds for this scale changed by 0.91 for every point increase in disagreement with statements that provider should make decisions about a patient's health (Table 3).

Multivariate Analyses

In logistic regression models adjusting for age, every scale was associated with decision-making in the same magnitude and direction as in the bivariate logistic analyses (Table 3).

Discussion

Over 80 percent of clients who participated in the IN-CARE baseline surveys reported joint decision-making about HIV treatment with their providers. This is a much higher level than reported in another recent study measuring perceived role in decisional control. Kremer et al. found that only 32% of their participants practiced joint decision-making. To measure this outcome, Kremer et al. used the Control Preferences Scale developed by Denger et al., which gave five different options for level of control, ranging from statements described as "fully passive" to "fully active." It may also be of interest to note that while the participants in that particular study experienced a very low level of shared decision-making, almost twice as many of them actually preferred the joint role. There were differences in the study population as well, which may also contribute to the substantial difference between Kremer et al.'s study and the IN-CARE study in the proportion of clients who experienced making choices about treatment in collaboration with their providers. The population was older and included women and fewer African Americans (17). In addition, we must also consider that the clients in the IN-CARE study did not take the survey immediately after their last appointment with their HIV provider. In fact, since only men who were either lost to care or newly diagnosed were eligible to participate, some of them may have had their last appointment several months or even years ago, and others may only have had just one appointment. This temporality issue may have several implications.

Preferred and perceived role in decision-making may be blurred for some clients.

Furthermore, clients who are either newly diagnosed or lost to care may participate

differently in decision-making about treatment than do their counterparts who do not fall

under either of those categories.

Despite a high level of shared decision-making reported, we found associations with

a few of our covariates. Black or African American men were over 3.5 times more likely to

play a passive as opposed to collaborative role in making decisions about treatment when

compared to white men. In addition, 92% of the white men in the study reported

experiencing joint decision-making with their providers; 80% of black men reported this

role. The IN-CARE study did not probe into the specifics of what may be happening during

the appointment to cause this result. Similar studies that have not specifically evaluated

decisional balance, but instead looked at patient-provider trust and at communications,

found that African Americans were less likely to have trust in their provider and also talked

less during their visits than the white patients (7, 21). It would not be unreasonable to

speculate that patients who do not feel empowered or distrust their providers may be

underlying factors associated with the lesser degree of decision-sharing in the study.

Another significant finding was that men who were over the age of 40 were more

likely to rely on their provider to make decisions than share in the process. We can also

conclude from the adjusted analyses that age and each of the scales are independent

associations. Other studies not focusing on HIV have found older age to be associated with

a preference for relying on the provider (30, 31, 32). While reported preference may differ

from actually experiencing passive decision-making overall, this may not be true for older

adults, which could help explain the similar findings between the IN-CARE analysis and the

previously cited studies. However, given that these studies were on illnesses other than HIV, there may be additional disease-specific differences.

We did not find that the degree to which clients feel their providers know them as a person was associated with a particular role in decision-making. In a study of preferred roles in decision-making with comparable age and race characteristics (but also included women), participants were more likely to report that their provider knows them as a person if they also preferred a passive role (17). Over 80% of their participants in that study felt that their provider knew them, and reported high levels of communication between patient and provider as well (17). A somewhat less proportion (70% overall) of clients in IN-CARE conveyed being known as a person, but this did not differ by role in decision-making. However, the Beach et al. study inquired about preferred as opposed to actual experiences in decision-making. Therefore, it may be that being known as a person is more important in the role a patient prefers to have, but not in the role that he actually experiences in his appointments with his provider. It should also be noted that even after collapsing "Strongly agree" with "Agree" and "Strongly disagree" with "Disagree", a few of the levels still had very low frequency, which affected our ability to detect statistical differences between the levels.

The Autonomy Preference Index was associated with a passive role in decision-making about treatment. Clients who disagreed with statements about the provider making decisions about a patient's health were more likely to collaborate in the process than assume a passive role. This was an unsurprising find, as the questions included in this index all were in regards to provider-directed decision-making (Appendix A). Examples include "The important medical decisions should be made by the provider, not the patient" and "If you

were sick and your condition became worse, you would want the provider to take greater control."

As far as sentiments about the general use of medications, not restricted to ARVs, clients who more strongly agreed with statements such as "Doctors prescribe too many medications," "Medications do more harm than good," and "All medications are poisons" were more likely to make the decisions themselves than in conjunction with their provider. One might suspect that mistrust of medications and doctors' uses of medications also could also translate to being wary of letting their provider participate in the decision-making process regarding treatment; however, the BMQ was not significantly associated with passive decision-making. Given that we were not able to assess differences in scores or each scale by race or ethnicity due to small cell counts, there may in actuality be important disparities by race/ethnicity. African Americans have reported a greater degree of skepticism surrounding HIV-specific treatment, but that skepticism could also have carried over into general use of medications as well (8).

The logistic regression analyses produced additional relationships between the scales and decisional balance on top of the Wilcoxon rank sum findings; however, the effect sizes were very small and median scores did not differ greatly. For the API, clients who reported higher disagreement with statements about the provider making decisions about a patient's health were less likely to share in decision-making with their provider than make the decisions themselves. Clients with lower social support from family, friends, coworkers, or anyone else in their lives, reported more sole decision-making as opposed to a joint role. Statements included "There is someone I could talk to about important decisions in my life" and "I feel I do not have close personal relationships with people." In another study involving people living with HIV, social support was associated with a greater level of

engagement in care, likely due both to physical support (i.e. transportation, financial assistance) and mental or emotional support in the form of motivation from family and friends (33). While that particular study did not specifically investigate decisional balance, these other factors affected by social support may also in turn have an impact on roles decision-making as well.

Strengths and Limitations

This was a cross-sectional study, so we may not claim causality surrounding the conclusions; we may only state that associations exist between the significant variables. Furthermore, since the study recruited only HIV positive MSM 18 or older in Chicago who are not in regular care for HIV, these results may not be generalized to other populations, including women, other transmission groups, youth, those consistently engaged in HIV care, or persons living in a non-urban setting.

Sparse and missing data were also a limitation to analysis. While we used Exact statistics to deal with low frequencies, some variables may be lacking in statistical power. Missing data did not pose significant problems in the bivariate analyses, but we were not able to perform multivariate analyses with more than two or three variables in each regression due to missing observations.

The baseline surveys consisted of two sections, one was self-administered, and the other was interviewer-administered. Each of these formats comes with their own limitations. The nature of the interview, inflections in the voice, or reaction to client responses may bias answers by unintentionally leading to a certain response or cause the client to not give truthful answers due to fear of judgment or discrimination by the interviewer. This may also happen to a certain extent from the self-administered survey. Literacy may also be a barrier

to this portion, where if a client is unable to comprehend a question, he may not be able to give an accurate answer.

Another limitation arises from the fact that all of the clients are either lost to care or newly diagnosed, so their either have had very few appointments with an HIV provider or it had been several months since their most recent appointments. Recall bias may be occurring from men who have not had a recent appointment; they may have had difficulties remembering the nature of the interactions with their providers. Although men who were newly diagnosed may have only had one appointment, just one experience can have a significant influence on future interactions with providers, or treatment adherence, and even whether he chooses to continue to be in care; one experience can impact his perception of the medical system, especially pertaining to HIV care. However, because of the temporality issue we were limited in not being able to use some of the available time-related variables, including whether or not they are currently receiving ART, and current relationship, housing, and health status.

Conclusions

This secondary analysis takes a step beyond other studies surrounding treatment and the HIV medical system by investigating the social and structural determinants of decision-making around treatment and the patient-provider relationship, including patient demographic characteristics, social support, sentiments around general use of medications, and attitudes towards the provider taking the lead in making decisions about a patient's health in different circumstances. While other studies have conducted basic exploratory analyses regarding demographic factors and engagement in care, this study also looks at this relationship in terms of social support, feelings about general use of medications, and general

thoughts on medical decision-making. Additionally, it gives providers and researchers designing intervention programs concrete demographic and social factors associated with a lesser degree of shared role in decision-making, including older men, African Americans, and those who prefer to rely on providers about health decisions or are skeptical about the general use of medications. These findings may be used to create environments that foster positive patient-provider relationships through empowering patients to engage more in their appointments and dispelling myths about treatment.

Table 1: Characteristics of clients who reported ever having an appointment with an HIV provider and gave a response for the question regarding how decisions about HIV treatment are made during appointments (N=331)

Variable	N (%)[1,2]
Mean Age (SD)	38.41 (10.3)
Missing	0
Age (categorical)	
18-40	177 (53.5)
41-65	154 (46.5)
Missing	0
Race (category)	
White	79 (25.2)
Black or African American	224 (71.3)
Other (American Indian or Alaska Native, Asian, Native Hawaiian or Other Pacific Islander)	11 (3.5)
Missing	17
Hispanic	
No	264 (81.5)
Yes	60 (18.5)
Missing	7
Highest level of education completed	
Less than high school	45 (15.6)
High school diploma or equivalent	80 (27.7)
Some college or technical school	111 (38.4)
College degree or higher	53 (18.3)
Missing	42
My provider knows me as a person (collapsed)	
Agree	221 (69.5)
Neither Agree nor Disagree	55 (17.3)
Disagree	42 (13.2)
Missing	13
Social Provisions Scale (sum=60)[3]	24.0 (10.0)
Missing	17
Autonomy Preference Index (sum=30)[3]	17.0 (6.0)
Missing	10
Beliefs About Medication Questionnaire (sum=40)[3]	29.0 (7.0)
Missing	27
Which best describes how decisions about your HIV treatment are made during your visits with your HIV care provider?	
I make most or all of the decisions	25 (7.6)
My provider and I make the decisions together	273 (82.5)
My provider makes most or all of the decisions	33 (10.0)
Missing	0

[1]% does not include missing observations
[2]May not add up to 100% due to rounding
[3]Median (IQR) reported instead of N (%)

Table 2: Bivariate analyses for clients who reported ever having an appointment with an HIV provider and gave a response for the question regarding how decisions about HIV treatment are made during appointments (N=331)

	My provider and I make the decisions together	I make most or all of the decisions			My provider makes most or all of the decisions		
	N (%)	N (%)	OR (95% CI)[1]	P-value[1]	N (%)	OR (95% CI)[1]	P-value[1]
Age (categorical)							
18-40 (ref)	149 (72.7)	17 (9.6)	1.00	-	11 (6.2)	1.00	-
41-65	124 (80.5)	8 (5.2)	0.57 (0.20, 1.44)	0.278	22 (14.3)	2.40 (1.07, 5.70)	0.033
Race (category)							
White (ref.)	73 (92.4)	3 (3.8)	1.00	-	3 (3.8)	1.00	-
Black or African American	180 (80.4)	17 (7.6)	2.29 (0.63, 12.57)	0.281	27 (12.1)	3.64 (1.07, 19.31)	0.036
Other	8 (72.7)	2 (18.2)	5.87 (0.43, 59.90)	0.202	1 (9.1)	2.99 (0.05, 42.71)	0.733
Hispanic							
No (ref.)	213 (80.7)	21 (8.0)	1.00	-	30 (11.4)	1.00	-
Yes	55 (91.7)	3 (5.0)	0.55 (0.10, 1.96)	0.516	2 (3.3)	0.26 (0.03, 1.08)	0.069
Highest level of education completed							
Less than high school	36 (80.0)	2 (4.4)	0.42 (0.04, 2.17)	0.442	7 (15.6)	3.22 (0.76, 16.04)	0.128
High school diploma or equivalent (ref.)	67 (83.8)	9 (11.3)	1.00	-	4 (5.0)	1.00	-
Some college or technical school	94 (84.7)	4 (3.6)	0.32 (0.07, 1.20)	0.102	13 (11.7)	2.31 (0.67, 10.14)	0.232
College degree or higher	46 (86.8)	2 (3.8)	0.33 (0.03, 1.68)	0.251	5 (9.4)	1.18 (0.37, 9.64)	0.598
My provider knows me as a person (collapsed)							
Agree (ref.)	187 (84.6)	15 (6.8)	1.00	-	19 (8.6)	1.00	-
Neither Agree nor Disagree	44 (80.0)	5 (9.1)	1.42 (0.38, 4.38)	0.694	6 (10.0)	1.34 (0.41, 3.76)	0.714
Disagree	33 (78.6)	2 (4.8)	0.76 (0.08, 3.50)	1.000	7 (16.7)	2.08 (0.68, 5.70)	0.209

[1] Ref. = My provider and I make the decisions together
[2] Median (IQR) reported for scales
[3] Wilcoxon rank sum test reported for scales

Table 2 continued

	My provider and I make the decisions together	I make most or all of the decisions			My provider makes most or all of the decisions		
	N (%)[2]	N (%)[2]	OR (95% CI)	P-value[1,3]	N (%)[2]	OR (95% CI)	P-value[1,3]
Sum Social Provisions Scale (SPS)	24.0 (9.0)	27.5 (14.0)	-	0.055	26.5 (9.5)	-	0.249
Sum Autonomy Preference Index (API)	17.0 (6.0)	19.0 (5.0)	-	0.069	14.0 (8.0)	-	0.032
Sum Beliefs About Medication Questionnaire (BMQ)	29.5 (7.0)	24.0 (11.0)	-	0.004	30.0 (7.5)	-	0.277

[1] Ref. = My provider and I make the decisions together
[2] Median (IQR) reported for scales
[3] Wilcoxon rank sum test reported for scales

Table 3: Analyses of scales unadjusted and adjusted for age for clients who reported ever having an appointment with an HIV provider and gave a response for the outcome question regarding how decisions about HIV treatment are made during the appointment (N=331)

	Unadjusted		Adjusted for age	
	OR (95% CI)[1]	P-value[1]	OR (95% CI)[1]	P-value[1]
Model 1				
Sum Social Provisions Scale (SPS)				
My provider and I make the decisions together	1.00	-	1.00	
I make most or all of the decisions	1.08 (1.03, 1.13)	0.002	1.08 (1.03, 1.12)	0.002
My provider makes most or all of the decisions	1.03 (0.98, 1.07)	0.246	1.03 (0.98, 1.08)	0.250
Model 2				
Sum Autonomy Preference Index (API)				
My provider and I make the decisions together	1.00	-	1.00	-
I make most or all of the decisions	1.10 (1.00, 1.22)	0.048	1.10 (1.00, 1.22)	0.048
My provider makes most or all of the decisions	0.91 (0.83, 0.99)	0.028	0.91 (0.83, 0.99)	0.036
Model 3				
Sum Beliefs About Medication Questionnaire (BMQ)				
My provider and I make the decisions together	1.00	-	1.00	-
I make most or all of the decisions	0.89 (0.83, 0.96)	0.003	0.89 (0.82, 0.96)	0.003
My provider makes most or all of the decisions	1.06 (0.98, 1.14)	0.174	1.06 (0.98, 1.15)	0.142

[1] Ref. = My provider and I make the decisions together

CHAPTER 3: PUBLIC HEALTH IMPLICATIONS AND RECOMMENDATIONS FOR FUTURE STUDIES

The clients involved in the IN-CARE study shared the decision-making with their providers to a much higher degree than in other similar studies (16). Despite this fact, we still found significant differences among some demographic and social factors. Black men in this study were more likely to have the provider make the majority of decisions about treatment than share the decision; a smaller proportion of black men than white men in the study gave this response (80% compared to 92%, respectively). It is widely recognized that there are racial and ethnic disparities in HIV prevalence and several aspects of care; for example, black or African American persons experience worse outcomes in HIV, including treatment uptake and adherence, and are less likely to have suppressed viral load (7). Previous studies have highlighted various aspects of patient-provider relationships that may be associated with these outcomes. African American patients communicated to a lesser degree with their providers than white patients did (21). In addition, among African American patients, trust in one's provider was significantly correlated with adherence to treatment (7). The researchers in this study recommend building trust between patients and providers among African American patients as a way to help lessen the gap in racial disparities in terms of adherence (7). Our analyses showed that among clients enrolled in IN-CARE, decisional balance in patient-provider relationships differs by race. It may be beneficial to further investigate potential associations between trust and role in decision-making.

In addition to racial disparities in trust, a greater amount of skepticism surrounding treatment and general HIV infection has been noted among the black community (8). The Beliefs About Medication Questionnaire (BMQ) was significant factor in decision-sharing among the IN-CARE study population when compared to client-led decision-making.

Several of the items in the scale had a tone of skepticism regarding general use of medications, and clients who reported making decisions about treatment by themselves reported scores that implied greater agreement with items. However, since this study had low cell counts for several variables, we were not able to stratify by race, to determine whether this skepticism differs by race or ethnicity. Future studies with larger sample sizes may be able to assess for additional potential confounders, and also stratify by potential mediators to further not only investigate this relationship, and the relationship with the other scales investigated in the study.

We also saw that age was a determinant in decision-making in older men. Studies evaluating factors associated with other chronic illness have found this to be true as well (30, 31, 32). However, we did not find that age was a confounding factor in each scale, meaning that the associations between decisional balance and the SPS, API, and BMQ were each independent of age. More research is needed to further investigate what other characteristics in older men may be related to the disparity in decisional balance by age. Furthermore, while age was not a confounder, it may in fact be an effect modifier, and stratified analysis by age alone, and age in conjunction with race may shine additional light on the matter.

The scales and demographic characteristics measured in this study are important in informing patient-provider relationships for MSM living in Chicago. The intervention aspect of IN-CARE and similar projects involving peer health navigators or community health workers could take into account these findings by adapting their methods and messaging by counseling and empowering their clients. The messaging should encourage patients to make a joint decision about treatment and other health matter with their providers, instead of having their HIV care providers make all decisions or making all of the decisions themselves. This is especially important among older clients and black clients, those who have negative

feelings about general use of medications, those who believe the provider should make all decisions about health in any situation, and those who report low social support. In addition to intervention on the patient side, Uphold et al., who focused on interventions to improve health care access and retention among people living with HIV, suggests that providers may not be well-prepared to communicate with racially and ethnically diverse patients (33). Cultural competency training may help patients and providers feel more comfortable with each other during visits and help eliminate discrimination or stigma coming from the provider (33). Beach et al. found that black patients talked less in their appointments with HIV providers and recommends interventions to involve communication around care and treatment. They suggest encouraging providers to ask patients more questions during visits, or implement efforts to coach and empower black patients (21).

While that finding was limited to race, those who lacked social support also may not have felt as comfortable speaking up in appointments. Level of social support is also a factor that, while having only a small effect size in the IN-CARE study, is also found to be important in findings in other studies, and could also be adapted into intervention programs by finding or providing social support for clients who may not have peer, familiar, or other social support in their lives (33, 34). Being surrounded by social networks enhances engagement in care, which may manifest in many ways, including financial support, or emotional and motivational support (33). People who lack support from peers or otherwise and are not used to or do not feel comfortable sharing new events or decisions in their lives may be less willing to let their provider help them make decisions about their HIV treatment. Social services organizations and HIV-centered support groups may help fill a need for those with inconsistent or absent social support networks (34).

The IN-CARE project has the benefit of being a longitudinal study. We analyzed only the baseline data from this multi-year study that has follow-ups every six months. It could be beneficial to conduct a longitudinal analysis on the follow-up data to investigate possible changes in patient-provider relationships and decision-making regarding treatment. Additionally IN-CARE collects information regarding whether a client is currently newly diagnosed or lost to care. While this information was not relevant for these analyses since a client could have been newly diagnosed when he last had an appointment with an HIV provider, but is now classified as lost to care since several months or years have passed, it could be a factor in the level of decision-making regarding treatment. Future studies that investigate decision-making among HIV positive MSM could also classify clients based on their new or lost to care status immediately following their latest appointment to determine whether this is an aspect of level of engagement. As far as we know, this has not been specifically evaluated in any study. Someone who is newly diagnosed with HIV may have different perceptions and expectations when going into their first appointment with an HIV provider than someone who has known their status for sometime, but is not consistently engaged in care. This could be especially beneficial to investigate since reasons for cycling in and out of care may be related to negative experiences a person had with a clinic or provider (6). In turn, these bad experiences may impact a patient's willingness or ability to equally engage in decision-making about treatment or other health issues.

Finally, there are countless other variables relating to social determinants of health that could be included in future studies, such as health literacy level, health insurance status, or even an expanded scale on engagement with provider, such as used in Bakken et al. (22) instead of relying on a single predictor.

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APPENDICES

Appendix A: Social Provisions Scale, Autonomy Preference Index, Beliefs About Medication Questionnaire

Responses for all items of each scale include "Strongly Disagree," "Disagree," "Neither Agree nor Disagree," "Agree," and "Strongly Agree."

Social Provisions Scale

1. I feel I do not have close personal relationships with other people.
2. There is no one I can turn to for guidance in times of stress.
3. I have close relationships that provide me with a sense of security and well-being.
4. There is someone I could talk to about important decisions in my life.
5. There is no one who shares my interests or concerns.
6. There is no one who really relies on me for their well-being.
7. There is a trustworthy person who I can turn to for advice if I were having problems.
8. I feel a strong emotional bond with at least one other person.
9. There is no one I can depend on for aid if I really need it.
10. There is no one I feel comfortable talking about my problems with.
11. There are people I can count on during an emergency.
12. No one needs me to care for them.

Autonomy Preference Index

1. The important medical decisions should be made by the provider, not the patient.
2. Patients should go along with the provider's advice, even if they disagree with it.
3. Hospitalized patients should not be making decisions about their own medical care.
4. Patients should feel free to make decisions about everyday medical problems.
5. If you were sick and your condition became worse, you would want the provider to take greater control.
6. Patients should decide how frequently they need a checkup.
7. My provider knows me as a person.

Beliefs About Medication Questionnaire

1. Doctors prescribe too many medications.
2. People who take medications should stop their treatment for a while every now and again.
3. Most medicines are addictive.
4. Natural remedies are safer than medications.
5. Medications do more harm than good.
6. All medications are poisons.
7. Doctors place too much trust on medications.
8. If doctors had more time with patients, they would prescribe fewer medications.

Appendix B: SAS Code

```
*---------------------------------------------------------------------;
*Eliminate clients who have never had an appointment;
*---------------------------------------------------------------------;

*Restrict dataset to those who have had not at least zero appts in the
last year where last appt year was not missing;
data noappt;
      set eligb;
      where elig6 gt 0 or elig6ayr ne .;
run;

*Also delete data where bam8 is missing;
data bam8nomiss;
      set noappt;
      where bam8 ne .;
run;




*----------------------------------------------------------------------;
*Datastep to prepare data for analysis. Includes category creation,
 collapsing of scales, and transformations of continuous variables;
*----------------------------------------------------------------------;

data analysis;
      set bam8nomiss;

      if bam8 = . then bam8o = .;
            else if bam8 = 1 then bam8o = 1;
            else if bam8 = 2 then bam8o = 2;
            else if bam8 = 3 then bam8o = 3;
      label bam8o = "Which best describes how decisions about HIV
treatment are made with your provider?";

      if bam8o eq 1 then bam8indiv = 1;
            else if bam8o eq 2 then  bam8indiv = 0;
            else if bam8o eq 3 then bam8indiv = .;
      if bam8o eq 3 then bam8prov = 1;
            else if bam8o eq 2 then  bam8prov = 0;
            else if bam8o eq 1 then bam8prov = .;
      label bam8indiv = "Binary with Individal Makes Decisions (1)"
              bam8prov = "Binary with Provider Makes Decisions (1)";

      *Race variable from baseline survey collapsed;
      if race = . then raceo = .;
            else if race = 5 then raceo = 1; *White;
            else if race = 3 then raceo = 2; *Black or African
American;
            else if race = 1 or race = 2 or race = 4 then raceo = 3;
*Other;
      label raceo = "Race with AIAN, Asian, and NH-OPI collapsed into
Other";
```

```sas
        *Provider knows me as person collapsed;
        if bam7 = . then bam7a = .;
                else if bam7 = 1 or bam7 = 2 then bam7a = 1;
                else if bam7 = 3 then bam7a = 2;
                else if bam7 = 4 or bam7 = 5 then bam7a = 3;
        label bam7a = "My provider knows me as a person - collapsed";

        *Hispanic recode;
        if hispanic = . then hisp = .;
                else if hispanic = 1 then hisp = 1;
                else if hispanic = 2 then hisp = 0;
        label hisp = "Hispanic recode 1=Yes, 0=No";

        *Reverse variables that need to be reversed;
        bam6r = 6- bam6;
                label bam6r = "Patients should feel free to make decisions
about everyday medical decisions - REVERSED";
        bam4r = 6- bam4;
                label bam4r = "Patients should decide how frequently they
need checkup - REVERSED";
        sps1r = 6- sps1;
                label sps1r = "I feel I do not have close personal
relationships with other people - REVERSED";
        sps2r = 6- sps2;
                label sps2r = "There is no one I can turn to for guidance
in times of stress - REVERSED";
        sps5r = 6- sps5;
                label sps5r = "There is no one who shares my interests or
concerns - REVERSED";
        sps6r = 6- sps6;
                label sps6r = "There is no one who really relies on me for
their well-being - REVERSED";
        sps9r = 6- sps9;
                label sps9r = "There is no one I can depend on for aid if I
really need it - REVERSED";
        sps10r = 6- sps10;
                label sps10r = "There is no one I feel comfortable talking
about my problems with - REVERSED";
        sps12r = 6- sps12;
                label sps12r = "No one needs me to care for them -
REVERSED";

        *Sum and avg. of Social Support questions;
        socialsum = sps1r + sps2r + sps3 + sps4 + sps5r + sps6r + sps7 +
sps8 + sps9r + sps10r + sps11 + sps12r;
                label socialsum = "Sum of Social Scale items";

        socialavg = socialsum/12;
                label socialavg = "Avg. of Social Scale items";

        *Sum and avg. of medical decision-making questions;
        meddecisionsum = bam1 + bam2 + bam3 + bam4r + bam5 + bam6r;
                label meddecisionsum = "Sum of Medical Decision-Making
items";

        meddecisionavg = meddecisionsum/6;
                label meddecisionavg = "Avg. of Medical Decision-Making
```

```
items";

      *Sum and avg. for general use of meds;
      generalmedsum = meds1 + meds2 + meds3 + meds4 + meds5 + meds6 +
meds7 + meds8;
            label generalmedsum = "Sum of general use of meds items";

      generalmedavg = generalmedsum/8;
            label generalmedavg = "Avg. of general use of meds items";

      *Sum and avg. for HIV stigma items;
      stigmasum = s1 + s2 + s3 + s4 + s5 + s6 + s7 + s8 + s9 + s10 +
s11 + s12;
            label stigmasum = "Sum of HIV stigma items";

      stigmaavg = stigmasum/12;
            label stigmaavg = "Avg. of HIV stigma items";

      *Transformations;
      logsocialsum = log(socialsum);
            label logsocialsum = "Log of sum of social scale";
      logsocialavg = log(socialavg);
            label logsocialavg = "Log of avg. of social scale";

      logmeddecsum = log(meddecisionsum);
            label logmeddecsum = "Log of sum of medical decision making
scale";
      logmeddecavg = log(meddecisionavg);
            label logmeddecavg = "Log of avg. of medical decision
making scale";

      llmeddecsum = log(log(meddecisionsum)); **log-log not
improvement!;
            label llmeddecsum = "Log-log of sum of medical decision
making scale";
      llmeddecavg = log(log(meddecisionavg)); **log-log not
improvement!;
            label llmeddecavg = "Log-log of avg. of medical decision
making scale";

      sqmeddecsum = meddecisionsum*meddecisionsum;
            label sqmeddecsum = "Square of sum of medical decision
making scale";

      sqsocialavg = socialavg*socialavg;
            label sqsocialavg = "Square of avg. of social scale";

      loggenmedsum = log(generalmedsum);
            label loggenmedsum = "Log of sum of general meds scale";
      loggenmedavg = log(generalmedavg);
            label loggenmedavg = "Log of avg. of general meds scale";

      logage = log(age);
            label logage = "Log of age (continuous)";

      *dichotomous age;
      if age ge 18 and age le 40 then aged = 0;
```

```
        if age ge 41 and age le 65 then aged = 1;
                label aged = "Dichotomous Age, where 0 is less than 41 and
1 is greater than 40";

    run;




    proc format;

        value hisp        0 = "Not Hispanic"
                          1 = "Hispanic"
                          . = "Missing";

        value raceo     1 = "White"
                        2 = "Black or African American"
                        3 = "Other";

        value bam8o     1 = "I make most or all of the decisions"
                        2 = "My provider and I make the decisions
together"
                        3 = "My provider makes most or all of the
decisions";

        value bam7a     1 = "Agree"
                        2 = "Neither agree nor disagree"
                        3 = "Disagree";

        value aged     0 = "18-40"
                       1 = "41-65";

    run;




    *-------------------------------------------------------------------;
    *Descriptives;
    *-------------------------------------------------------------------;


    *Frequencies of categorical variables;
    %macro freq(var1, format1, format2);

    proc freq data=analysis;
        table &var1 / list;
        format &format1 &format2;
    run;

    %mend;

    %freq(bam8o, bam8o, bam8o.); *how HIV treatment decisions are made;
    %freq(bam7a, bam7a, bam7a.); *my provider knows me as a person;
    %freq(raceo, raceo, raceo.); *race from baseline form;
    %freq(hisp, hisp, hisp.); *whether client is hispanic;
    %freq(educ, educ, educ.); *client highest level of education;
    %freq(aged, aged, aged.); *age in two categories;
```

```
*Frequencies of categorical variables by level of decision-making;
*Restricted dataset;
%macro freq(var1, level, format1, format2);

proc freq data=analysis; where bam8o ne &level;
      table &var1 / list;
      format &format1 &format2 bam8o bam8o.;
run;

%mend;


%freq(raceo, 1, raceo, raceo.); *race from baseline form;
%freq(raceo, 3, raceo, raceo.); *race from baseline form;
%freq(hisp, 1, hisp, hisp.); *where client is hispanic;
%freq(hisp, 3, hisp, hisp.); *where client is hispanic;
%freq(educ, 1, educ, educ.); *client highest level of education;
%freq(educ, 3, educ, educ.); *client highest level of education;
%freq(aged, 1, aged, aged.); *age in two categories;
%freq(aged, 3, aged, aged.); *age in two categories;
%freq(bam7a, 1, bam7a, bam7a.); *age in two categories;
%freq(bam7a, 3, bam7a, bam7a.); *age in two categories;


*Determine overall median, IQR for each scale;
%macro univar(var);
proc univariate data=analysis;
      var &var;
run;
%mend;


%univar(socialsum);
%univar(meddecisionsum);
%univar(generalmedsum);


*Determine median, IQR for each scale by level of decision-making;
%macro univar(var);
proc univariate data=analysis;
      class bam8o;
      var &var;
      format bam8o bam8o.;
run;
%mend;

%univar(socialsum);
%univar(meddecisionsum);
%univar(generalmedsum);


*Determine Cronbach alpha;
*social support (SPS);
proc corr data = analysis alpha nomiss;
var  sps1r sps2r sps3 sps4 sps5r sps6r sps7 sps8 sps9r sps10r sps11
sps12r ;
run;
```

```sas
*Medical decision-making (API);
proc corr data = analysis alpha nomiss;
var bam1 bam2 bam3 bam4r bam5 bam6r ;
run;

*general use of meds (BMQ);
proc corr data = analysis alpha nomiss;
var  meds1 meds2 meds3 meds4 meds5 meds6 meds7 meds8 ;
run;



*Assess violation of normality assumptions;
%macro logit(dataset, bam8level, var, levelname);
proc rank data=&dataset groups=15 out=ranks10;
     var &var;
     ranks bin10;
run;

proc means data=ranks10 noprint nway;
     class bin10;
     var &bam8level &var;
     output out=bins10 sum(&bam8level)= &bam8level mean(&var)= &var;
run;

data bins10;
     set bins10;
     logit=((&bam8level+1)/(_freq_-&bam8level+1));
run;

Title "&var, &levelname vs. Shared Decision";
proc gplot data=bins10;
     plot logit*&var;
     symbol v=star i=none;
run;

quit;

%mend;

%logit(analysis, bam8indiv, Age, Individual);
%logit(analysis, bam8prov, Age, Provider);
%logit(analysis, bam8indiv, Socialsum, Individual);
%logit(analysis, bam8prov, Socialsum, Provider);
%logit(analysis, bam8indiv, Meddecisionsum, Individual);
%logit(analysis, bam8prov, Meddecisionsum, Provider);
%logit(analysis, bam8indiv, Generalmedsum, Individual);
%logit(analysis, bam8prov, Generalmedsum, Provider);
%logit(age, bam8indiv, aged, Individual);
%logit(age, bam8prov, aged, Provider);
```

```
*------------------------------------------------------------------;
*Modeling;
*------------------------------------------------------------------;

*Logistic regressions for each categorical variable;

proc logistic data=analysis desc; where bam8o ne 1;
      class bam8o (ref = "My provider and I make the decisions
together")  hisp (ref = "Not Hispanic")/ param = ref;
      model bam8o = hisp; exact hisp / estimate = both; format bam8o
bam8o.      hisp hisp.;
run;

proc logistic data=analysis desc; where bam8o ne 3;
      class bam8o (ref = "My provider and I make the decisions
together")  hisp (ref = "Not Hispanic")/ param = ref;
      model bam8o = hisp; exact hisp / estimate = both; format bam8o
bam8o.      hisp hisp.;
run;

proc logistic data=analysis desc; where bam8o ne 1;
      class bam8o (ref = "My provider and I make the decisions
together")  raceo (ref = "White")/ param = ref;
      model bam8o = raceo; exact raceo / estimate = both; format bam8o
bam8o.      raceo raceo.;
run;

proc logistic data=analysis desc; where bam8o ne 3;
      class bam8o (ref = "My provider and I make the decisions
together")  raceo (ref = "White")/ param = ref;
      model bam8o = raceo; exact raceo / estimate = both; format bam8o
bam8o.      raceo raceo.;
run;

proc logistic data=analysis ; where bam8o ne 1;
      class bam8o (ref = "My provider and I make the decisions
together")  aged (ref = "18-40")/ param = ref;
      model bam8o = aged; exact aged / estimate = both; format bam8o
bam8o.      aged aged.;
run;

proc logistic data=analysis ; where bam8o ne 3;
      class bam8o (ref = "My provider and I make the decisions
together")  aged (ref = "18-40")/ param = ref;
      model bam8o = aged; exact aged / estimate = both; format bam8o
bam8o.      aged aged.;
run;

proc logistic data=analysis; where bam8o ne 1;
      class bam8o (ref = "My provider and I make the decisions
together")  educ (ref = "High school diploma or equivalent")/ param =
ref;
      model bam8o = educ; exact educ / estimate = both; format bam8o
bam8o.      educ educ.;
run;
```

```
proc logistic data=analysis; where bam8o ne 3;
      class bam8o (ref = "My provider and I make the decisions
together")  educ (ref = "High school diploma or equivalent")/ param =
ref;
      model bam8o = educ; exact educ / estimate = both; format bam8o
bam8o.      educ educ.;
run;


proc logistic data=analysis desc; where bam8o ne 1;
      class bam8o (ref = "My provider and I make the decisions
together")  bam7a (ref = "Neither agree nor disagree")/ param = ref;
      model bam8o = bam7a; exact bam7a / estimate = both; format bam8o
bam8o.      bam7a bam7a.;
run;


proc logistic data=analysis desc; where bam8o ne 3;
      class bam8o (ref = "My provider and I make the decisions
together")  bam7a (ref = "Neither agree nor disagree")/ param = ref;
      model bam8o = bam7a; exact bam7a / estimate = both; format bam8o
bam8o.      bam7a bam7a.;
run;



*Wilcoxon rank sum test for each scale;
%macro wc(level, var);
proc npar1way data=analysis wilcoxon; where bam8o ne &level;
      class bam8o;
      var &var;
      format bam8o bam8o.;
run;
%mend;

%wc(1, socialsum);
%wc(3, socialsum);
%wc(1, meddecisionsum);
%wc(3, meddecisionsum);
%wc(1, generalmedsum);
%wc(3, generalmedsum);
%wc(1, stigmasum);
%wc(3, stigmasum);




*---------------------------------------------------------------------;
*Assessment for confounding;
*---------------------------------------------------------------------;

*Unadjusted logistic regressions for each scale;
%macro adj(level, var);
proc logistic data=analysis ;
where bam8o ne &level;
      class bam8o (ref = "My provider and I make the decisions
together")  /    param = ref;
      model bam8o =  &var  / lackfit; format bam8o bam8o.;
run;
```

```
%mend;

%adj(1, socialsum);
%adj(3, socialsum);
%adj(1, meddecisionsum);
%adj(3, meddecisionsum);
%adj(1, generalmedsum);
%adj(3, generalmedsum);


*Logistic regressions for each scale, adjusted for age;
%macro adj(level, var);
proc logistic data=analysis ;
where bam8o ne &level;
     class bam8o (ref = "My provider and I make the decisions
together") aged (ref = '18-40') / param = ref;
     model bam8o =  &var  aged / lackfit; format bam8o bam8o. aged
aged.;
run;

%mend;

%adj(1, socialsum);
%adj(3, socialsum);
%adj(1, meddecisionsum);
%adj(3, meddecisionsum);
%adj(1, generalmedsum);
%adj(3, generalmedsum);
```