Decision-Making Role Preferences Among Patients with HIV: Associations with Patient and Provider Characteristics and Communication Behaviors

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BACKGROUND: A preference for shared decision-making among patients with HIV has been associated with better health outcomes. One possible explanation for this association is that patients who prefer a more active role in decision-making are more engaged in the communication process during encounters with their providers. Little is known, however, about patient and provider characteristics or communication behaviors associated with patient decision-making preferences in HIV settings.

OBJECTIVE: We examined patient and provider characteristics and patient-provider communication behaviors associated with the decision-making role preferences of patients with HIV.

DESIGN: Cross-sectional analysis of patient and provider questionnaires and audio recorded clinical encounters from four sites.

PARTICIPANTS: A total of 45 providers and 434 of their patients with HIV.

MEASURES: Patients were asked how they prefer to be involved in the decision-making process (doctor makes all/most decisions, patients and doctors share decisions, or patients make decisions alone). Measures of provider and patient communication behaviors were coded from audio recordings using the Roter Interaction Analysis System.

MAIN RESULTS: Overall, 72% of patients preferred to share decisions with their provider, 23% wanted their provider to make decisions, and 5% wanted to make decisions themselves. Compared to patients who preferred to share decisions with their provider, patients who preferred their provider make decisions were less likely to be above the age of 60 (ARR 0.09, 95% CI 0.01–0.89) and perceive high quality provider communication about decision-making (ARR 0.41, 95% CI 0.23–0.73), and more likely to have depressive symptoms (ARR 1.92, 95% CI 1.07–3.44). There was no significant association between patient preferences and measures of provider or patient communication behavior.

CONCLUSION: Observed measures of patient and provider communication behavior were similar across all patient decision-making role preferences, indicating that it may be difficult for providers to determine these preferences based solely on communication behavior. Engaging patients in open discussion about decision-making preferences may be a more effective approach.

KEY WORDS: HIV; communication; decision-making preferences.

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BACKGROUND

Although patient participation in clinical decision-making has evolved over the last century with the transition from a paternalistic paradigm to a consumerist one, the extent to which patients want to be involved in the decision-making process is not always clear. Patient preferences for engagement in health-related decisions have been described using three models^{1–4}: the paternalistic model where the provider makes decisions based on what he/she thinks is in the best interest of the patient, the shared model where the provider and patient exchange information and make decisions together, and the consumerist model where the provider presents information to the patient who makes the final decision.

Because of several studies showing improved treatment adherence in chronic disease management with increased patient participation in the medical visit,^{5–7} health care providers have become increasingly interested in the patient's role in the decision-making process and factors that impact patient role preferences. However, findings among patients with chronic diseases including hypertension, diabetes, asthma, or depression have been mixed thus far, with some studies finding an association between patient characteristics such as younger age, female gender, or increased education level and a preference for an active decision-making role preference^{8–12} and others finding no association between these characteristics and patient preferences in multivariate models^{13–15}.

Understanding decision-making preferences is particularly pertinent for providers of patients with HIV who routinely make complex decisions involving treatment initiation and medication adherence. Further, with recent advances in the

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treatment of HIV infection, providers are now managing HIV infection as another chronic disease in which mechanisms to improve treatment adherence would be especially useful. While qualitative studies suggest patients with HIV highly value involvement in treatment decisions,^{16,17} few quantitative studies have investigated their decision-making preferences. To this end, Beach et al. found that 63% of patients with HIV preferred shared decision-making and that these patients were more likely to adhere to antiretroviral therapy than those who preferred their providers make decisions¹⁸, suggesting that increased patient participation in the setting of HIV may lead to increased treatment adherence.

One possible explanation for the association between patient decision-making role preferences and clinical outcomes is that patients who prefer a more active role in decision-making are more engaged in the communication process during encounters with their providers. Increased patient participation may then lead to increased understanding of the treatment rationale, perception of control over health⁶, and adherence to provider recommendations¹⁹, resulting in improved clinical outcomes. However, how patient and provider characteristics or communication behaviors may be associated with patient decision-making preferences in HIV settings is still unknown. We hypothesized that patients who demonstrated more engaged communication behaviors and whose providers engaged in more rapport-building and patient activation behaviors would be more likely to prefer a more active role in decision-making. To this end, the objective of our study was to examine patient and provider characteristics associated with decision-making role preference among a sample of patients with HIV, and to determine the association between patient decision-making role preference and patient and provider communication behaviors.

METHODS

Study Design, Subjects, and Setting

The Enhancing Communication and HIV Outcomes (ECHO) Study was a multi-site study of disparities in the interpersonal quality of HIV care conducted between December 2004 and January 2006. At four sites (Baltimore, Detroit, New York, and Portland), HIV providers (physicians, nurse practitioners, and physician assistants who provided primary HIV care), and their patients completed questionnaires about communication and decision-making. Eligible patients had at least one prior visit with their provider and were HIV-infected, 20 years of age or above, and English-speaking. Providers gave informed consent to complete a baseline questionnaire of attitudinal measures after which research assistants approached patients in the waiting rooms, attempting to enroll ten patients per provider. Patients and providers gave written informed consent to have their encounters audiotaped. Following the encounter, trained research assistants interviewed the patients and collected information on demographics; social, behavioral, and clinical characteristics; experience of care; and ratings of provider communication. Patients were compensated \$50 for participation. The study was approved by the Institutional Review Board at each of the four sites.

Measures

We used a single question developed by Brody et al.²⁰ to assess the patient's preferred decision-making role. Research assistants asked patients to assess their preferences after the clinical visit, but they specifically asked the patient to think about health decisions in general, and not a particular decision or those that took place in the visit just prior to the interview. Patients answered the question: "What role do you want to play in your medical care?" with one of four responses: (1) the doctor takes initiative and decides what is best for me, (2) the doctor considers some of my ideas but still makes most, if not all, of the final decisions, (3) the doctor and I make the final decisions together, and (4) I make all of the final decisions. Responses "1" and "2" were combined for the analysis since they both reflected a patient's desire for a provider-centered decision-making role.

Provider characteristics included self-reported race/ethnicity, gender, and age. Due to the small sample size of African-American (n=2) and Latino (n=1) providers, these groups were combined in the analysis. Patient characteristics included self-reported age, race/ethnicity, sex, employment, education, and substance abuse²¹. Depression was assessed using the CESD-10 screening instrument²². Patients rated the quality of their provider's communication about decision-making using the six-item subscale of the Interpersonal Processes of Care Survey²³ (Cronbach alpha 0.65), which consisted of the following questions: "how often did your HIV provider (1) try to involve you or include you in decisions about your treatment, (2) ask how you felt about different treatments, (3) make decisions without taking your preferences or opinions into account, (4) make you feel pressured to have a treatment you were not sure you wanted, (5) ask if you might have any problems doing the recommended treatment, and (6) understand the kinds of problems you might have in doing the recommended treatment." Patient satisfaction with care was assessed by asking patients to rate their overall experiences with their physician as excellent, very good, good, fair, or poor^{24,25}. Information on antiretroviral regimen, HIV RNA, and CD4 count were abstracted from the patient's medical record.

Audiotapes of clinical encounters were analyzed using the Roter Interaction Analysis System (RIAS), a widely used coding system to assess patient and provider communication behaviors during medical encounters with well-documented reliability and predictive validity²⁶⁻³⁰. Two women coded all audio recordings using the RIAS, assigning 1 of 37 mutually exclusive and exhaustive categories to each complete thought expressed by the patient or provider (referred to as an utterance). In this study, we focused on select provider (rapport-building and patient engagement) and patient behaviors (question-asking and activation) as well as summary measures (visit length, verbal dominance, and patient-centeredness). Provider rapport-building consisted of use of emotional talk (statements that were legitimizing, expressed concern/worry, reassurance/optimism, partnership, and self-disclosure), positive talk (laughs/jokes, approval directed at the other person, compliment given to someone not present during the exchange, and showing agreement/understanding), negative talk (disagreement/criticism directed at anyone), and social chit-chat. Provider engagement included behaviors such as asking for patients' opinions and checking for patient understanding. Patient question-asking consisted of both biomedical and psychosocial/lifestyle questions.

Patient activation included behaviors such as asking for a service and asking for provider understanding. The overall intercoder reliability was calculated using Pearson's correlation coefficient on a random sample of 41 audiotapes and ranged from 0.71 to 0.95 across categories of patient and provider behaviors. The summary measures evaluated through RIAS coding included verbal dominance (ratio of provider to patient utterances), visit length, and patient-centeredness (ratio of psychosocial and emotional talk to biomedical talk).

Analysis

We compared patient and provider characteristics across decision-making role preference using chi-squared tests. Using preference for shared decision-making as the reference group, we conducted bivariate and multivariate multinomial logistic regression analyses to examine the association between patient and provider characteristics and decision-making role preference. Since only 20 out of 434 patients preferred to make decisions alone, we restricted the remainder of the analysis to 414 patients. Variables with a p value of < 0.20 in bivariate analysis were considered for inclusion in the multivariate model. We used negative binomial regression to compare how observed measures of patient-provider communication behavior vary by decision-making role preference. Twenty patients had missing RIAS data due to recorder malfunction. These patients were excluded from analysis on communication behaviors. Bivariate and multivariate analyses used generalized estimating equations to adjust for site and account for nested clustering of patients within providers. All data analyses were conducted using Stata Version 10.0.

RESULTS

Study Sample

Of the 55 providers eligible for the study, 45 enrolled in the study (82%). These 45 providers had 617 eligible patients, of which 435 (73%) agreed to participate and completed all study procedures. The most common reasons for patient refusal were not enough time to complete the interview ($n=106$), not feeling well ($n=22$), and not being interested ($n=13$). Data on decision-making role preference were missing for one patient, resulting in a study sample of 434 patients. The characteristics of the study sample are shown in Table 1.

Association of Patient and Provider Characteristics with Patient Decision-Making Role Preference

In bivariate analysis (Table 1), patients who preferred shared vs. provider-made decisions were more likely to be African American than white (63.4% vs. 44.0%, $p<0.05$). Compared to those who preferred to make shared decisions, patients who preferred their provider make decisions were more likely to screen positive for depression (72.0 % vs. 54.5%, $p<0.05$) and less likely to perceive high levels of provider communication about decision-making (26.3% vs. 40.8%, $p<0.05$).

In multivariate analyses (Table 2), the association between race and decision-making role preference was not statistically significant. Patients between 40 and 50 years of age (ARR 0.58,

95% CI 0.33–1.01) and those above the age of 60 (ARR 0.09, 95% CI 0.01–0.89) were less likely than those below 40 to prefer their provider make decisions. Further, compared to patients who preferred to make shared decisions with their provider, patients who screened positive for depression (ARR 1.92, 95% CI 1.07–3.44) and those who were very satisfied with their care (ARR 1.90, 95% CI 1.13–3.19) were more likely to prefer their provider make decisions. Patients who perceived high levels rather than low levels of provider communication about decision-making were less likely to prefer their provider make decisions (ARR 0.41, 95% CI 0.23–0.73).

Association of Patient Decision-Making Role Preferences with Patient and Provider Communication Behaviors

Table 3 displays the results of multivariate analysis evaluating the association between patient-provider communication behaviors and preference for the provider to make decisions compared to making shared decisions. Provider behaviors, patient behaviors, and RIAS summary measures did not differ by patient decision-making role preference. There were no significant differences across patient preference in the realms of positive, negative, emotional, or social talk within provider rapport-building.

DISCUSSION

To our knowledge, our study is the first to explore the association between observed patient-provider communication behaviors and decision-making preference in patients with HIV. We found that the majority of patients preferred a shared decision-making role and that patient age, depression, care satisfaction, and ratings of provider communication were associated with patient decision-making role preference. However, we also found little difference in observed measures of patient and provider communication behaviors among patients with different decision-making role preferences. This is similar to recent findings from a study of older patients and their orthopedic surgeons³¹ and suggests that patients' decision-making role preference may not manifest in their communication behaviors during the clinic visit. Alternatively, it is possible that despite wanting a more active role in the decision-making process, many patients don't have the tools to convey this preference in communication with their provider.

Although measures of observed provider behavior did not differ according to decision-making role preference, we found that patients who rated the quality of their providers' communication highly preferred to share decision-making rather than wanting their providers to make decisions. There are several possible explanations for this finding. First, differences in provider communication about decision-making may not have been reflected in the particular communication behaviors analyzed with the RIAS. Although we chose behaviors that have been traditionally thought to encourage patient participation in care, we may be overlooking other measures that are specific to the decision-making process. Second, certain provider communication behaviors may be predictive of decision-making role preference only in the context of multiple clinic visits over time rather than a single visit as

Table 1. Participant Characteristics by Patient Decision-Making Role Preference

	Total sample	Preference for provider to make decisions (n=100)	Preference for shared decision-making (n=314)	Preference for patient to make decisions (n=20)
Patient characteristics (n=434) ^a				
Age-years				
Mean (SD)	45.4 (9.4)	43.1 (9.3)	46.0 (9.4)	46.6 (8.6)
Gender (%)				
Female	34.0	31.3	36.0	15.0
Race (%)				
Non-Hispanic White	23.3	31.0	20.1	35.0
African American	57.6	44.0 ^d	63.4	35.0
Latino	13.8	21.0	11.8	10.0
Other	5.3	4.0	4.8	20.0
High school degree (%)				
Yes	72.4	78.0	70.7	70.0
Employment status (%)				
Working	25.4	30.0	25.2	5.0
On HAART (%) ^f				
Yes	78.6	73.2	80.3	79.0
Viral load (%)				
≤400	63.1	60.8	62.8	79.0
Depression-CESD10 (%) ^b				
≥10	58.3	72.0 ^d	54.5	50.0
Alcohol use (%)				
Never	40.6	37.0	43.3	15.0
Former	49.5	48.0	48.4	75.0
Current	9.9	15.0	75.0	10.0
Active drug use (%)				
Yes	28.8	36.0	25.8	40.0
Length of provider-patient relationship (%)				
>5 years	33.3	30.6	33.8	40.0
Overall satisfaction with care (%)				
Highest rating	62.0	70.0	60.5	45.0
Communication about decision-making (%) ^c				
Highest rating	37.2	26.3 ^d	40.8	35.0
Provider characteristics (n=45)				
Age-years				
Mean (SD)	44.5 (8.1)	46.5 (8.0)	43.9 (8.2)	44.2 (7.2)
Gender (%)				
Female	55.6	53.0	59.2	60.0
Race (%)				
Non-Hispanic White	70.7	82.0	66.2	85.0
Asian	20.3	14.0	22.9	10.0
Other	9.0	4.0	10.8	5.0

Analysis of variance was calculated for continuous variables, and chi-squared tests were used for dichotomous variables. *P* values are based on bivariate analysis conducted using multinomial logistic regression and accounted for clustering by site and provider. Preference for shared decision-making was used as the reference category

^aBecause of missing data, the total sample size for individual patient variables ranged from 432 to 434

^bCESD10 refers to the validated, shorter version of the CESD scale for depression. Patients with scores of 10 or above are considered depressed

^cPerceived quality of provider communication about decision-making was assessed through patient ratings on the 6-item decision-making subscale of the Interpersonal Processes of Care Survey

^d*p*<0.05; compared to preference for shared decision-making

^e*p*<0.01; compared to preference for shared decision-making

^fEstimates include the entire sample. There were also no differences in decision-making role preference for patients when limiting the comparison to those on HAART with those eligible (based on CD4<350) yet not on HAART

was used in our study. Third, there could be an association between non-verbal communication and patient rating of provider's communication about decision-making that we were unable to capture through the audiotaped encounters. Future research may be able to provide insight into the effects of multiple clinic visits and non-verbal communication measures on patient preferences through the use of longitudinal studies and videotaped clinical encounters.

Our study also found that preference for shared decision-making did not significantly differ between whites and African Americans in contrast with two studies in which African Americans were more likely to prefer their provider make decisions compared to

whites^{32,33}. It is worth noting that fewer than half of the participants preferred an active role in the decision-making process in those studies. In contrast, the majority of patients (72%) in our study preferred a shared decision-making role, mirroring findings from other studies assessing decision-making preferences in patients with HIV^{34,35}. Our study results suggest that differences in patient engagement level between African American and white patients³⁶ might not reflect a decreased preference for involvement in the decision-making process. Rather, other provider and patient factors such as health literacy, self-efficacy, and provider biases may explain these disparities within patient participation and merit further exploration.

Table 2. Multivariate Relative Risk of Patient Preference for Provider to Make Decisions

	Preference for provider to make decisions ^a		
	RR	95% CI	P value*
Age			
<40 years (reference)	1.00		
40–50 years	0.58	(0.33–1.01)	0.05
50–60 years	0.59	(0.31–1.13)	0.11
>60 years	0.09	(0.01–0.89)	0.04
Race/ethnicity			
White, not Hispanic (reference)	1.00		
African American	0.60	(0.32–1.12)	0.11
Latino	1.23	(0.62–2.42)	0.56
Other	0.65	(0.14–2.99)	0.58
Gender			
Female (reference)	1.00		
Male	1.08	(0.61–1.93)	0.80
High school degree			
No (reference)	1.00		
Yes	1.39	(0.78–2.47)	0.27
Depression			
CESD <10 (reference)	1.00		
CESD ≥10	1.92	(1.07–3.44)	0.03
Overall satisfaction with care			
Less than high (reference)	1.00		
High	1.90	(1.13–3.19)	0.02
Perceived quality of provider communication about decision-making			
Less than high (reference)	1.00		
High	0.41	(0.23–0.73)	<0.01

*Compared to patient preference for shared decision-making

^aAdjusted for age, depression, overall satisfaction with care, and perceived quality of provider communication about decision-making. Results from the most parsimonious multivariate model are presented above. The multivariate models which included adjustment by gender, education, race, viral load, alcohol use, and provider characteristics did not significantly alter the results presented

We also found that patients with depressive symptoms were more likely to prefer delegating decisions to providers. Although a prior study found that patients with depression were more likely to prefer an active role than patients with other conditions, the effect of depression in the setting of chronic disease was not evaluated⁹. Another study found that while patients with all severity grades of depression were highly interested in receiving information, they were not as highly interested in participating in treatment decision-making³⁷, and qualitative work indicates that patients with depression may be less likely to engage in care because of feelings of low self-worth and assertiveness³⁸. Additional research could determine whether efforts to address these underlying issues enable providers to encourage patient participation in the decision-making process.

In contrast with several other studies^{8–11}, we did not find associations among patient characteristics of younger age, female gender, or higher level of education and an increased preference for a more active role in the decision-making process. We found instead that older compared to younger patients were more likely to prefer sharing decisions. Perhaps the effects of age on decision-making preferences are different in HIV care, where the median age is much younger than in diseases such as cancer, which has been the focus of prior studies on decision-making preference. Interestingly, a study of asthmatics¹³ in which the mean age of participants was

41 years also found no association between older age and preference for a passive role in decision-making after adjusting for educational status. In contrast with other studies, our study population had a relatively high number of high school-educated individuals (72%), which may help explain why we did not observe an association between lower levels of education and preference for the provider to make decisions.

One important consideration when interpreting the results of our study is that decision-making role preference was assessed at a single time point, *after* the audio recorded patient-provider encounter. While patients were asked about general decision-making preferences rather than specific treatment decisions that may have been discussed during that visit, it is possible that a patient's perception of the visit could have affected his/her reported decision-making role preference. To the extent that patients were reacting to that day's visit, it would be difficult to infer that their decision-making preference (as assessed after the visit) was able to influence their behavior in the visit, but relatively easier to imagine that the provider's behavior in that visit was able to influence the patients decision-making preference. On the other hand, most of our patients had a long-term relationship with their HIV care provider, and we believe that patients' decision-making preferences have been shaped by their own characteristics as well as the cumulative effect of multiple visits with that provider. Therefore, for practical purposes, we consider this study to be cross-sectional, capturing a single point in time in the patient-provider relationship. In terms of precedent, the study by Hudak et al.³¹ also assessed patient preferences after

Table 3. Association Between Patient Decision-Making Role Preference and Communication in Medical Visit

	Multivariate model ^a	
	Preference for provider to make decisions	Preference for shared decision-making
	Mean (95% CI)	Mean (95% CI)
Summary measures		
Verbal dominance (ratio)	1.6 (1.4–1.8)	1.6 (1.4–1.8)
Patient-centeredness (ratio)	0.8 (0.6–1.0)	0.7 (0.6–1.0)
Visit length (minutes)	23.2 (20.1–26.8)	25.4 (22.0–29.4)
Provider behaviors		
Patient engagement	48.8 (36.2–65.8)	50.4 (38.0–67.5)
Rapport-building	84.6 (71.8–99.7)	91.1 (71.0–107.9)
Positive talk	49.6 (40.1–61.3)	54.7 (44.2–67.7)
Negative talk	0.6 (0.4–1.1)	0.7 (0.4–1.2)
Emotional talk	30.3 (24.2–38.0)	32.9 (26.6–40.6)
Personal talk	4.5 (2.7–7.8)	3.8 (2.2–6.3)
Patient behaviors ^b		
Question-asking	7.2 (5.4–9.6)	7.4 (5.8–9.2)
Activation	8.0 (5.6–11.5)	7.9 (5.9–10.4)

Analysis conducted using negative binomial regression; means represent number of statements made by the patient in a specific category (categories described in detail in the Methods section)

^aAdjusted for age, depression, overall satisfaction with care, and perceived quality of provider communication about decision-making

^bAdditional analyses adjusting for provider communication behaviors on patient communication behaviors did not significantly alter results

the clinic visit allowing them to evaluate the impact of provider communication behavior on decision-making role preference.

This study has other potential limitations. First, the patient questionnaires were administered by research assistants resulting in the potential for social desirability bias. Next, participants were English-speaking, and the majority of providers were white. Therefore, generalizability of our results to other patient and provider populations is limited, and we could not evaluate the association between patient-provider racial/ethnic concordance and patient decision-making role preference. Lastly, we were unable to assess the reliability of the single-item measure we used to assess general decision-making role preferences, and generalizability of our results to specific decision-making contexts, such as initiation of antiretroviral treatment, may be limited.

Our results indicate that patients with HIV may be particularly interested in taking a collaborative approach to decision-making, but that depressive symptoms may affect patients' level of engagement. Providers should be wary of assuming their African-American patients and older patients are more likely to prefer a passive role and should foster communication about decision-making preferences with these patients as with others. While the current research provides insight into some of the factors associated with patient preferences, fully understanding decision-making preference remains a challenging task. Directions for future research include assessment of preferences over time, identification of provider behaviors that affect patient preferences, and development of tools to improve communication behaviors among patients who desire a more active role in the decision-making process. Based on our findings, providers should not assume patient preferences from simply observing patient communication behaviors, but rather should consider engaging their patients in explicit discussions about decision-making preferences.

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