A Mixed Methods Approach to Understanding Antiretroviral Treatment Preferences: What Do Patients Really Want?

Valerie Yelverton, BSc,^{1,2} Jan Ostermann, PhD,^{2,3} Amy Hobbie, MPH,³
Deng Madut, MD,⁴ and Nathan Thielman, MD, MPH^{3,4}

Abstract

As the number of effective antiretroviral therapy (ART) options increases, there is greater opportunity to involve HIV patients in ART selection. To establish the parameters for a shared ART decision-making process, we sought to identify ART characteristics that are important to patients and understand considerations in ART selection from both patient and provider perspectives. Using a mixed-methods approach, 16 patients and 12 healthcare providers were interviewed, and ranking tasks were conducted with 26 patients to identify ART characteristics that are relevant for shared decision making. Interviews were coded using direct content analysis and complemented by a quantitative analysis of references to specific attributes. Ranking data were analyzed through count analysis. Qualitative analysis of patient interviews identified four major categories of ART characteristics that are pertinent to shared decision making: side effects (14/16 patients), administration characteristics (14/16 patients), dosing (13/16 patients), and long-term effects (12/16 patients). Other considerations included expectations for patient involvement in ART decision making, relationship with provider, and efficacy. The degree of concordance between patients and providers differed across categories. Ranking exercises demonstrated differences in the ways providers and patients prioritize specific side effects and food requirements. Expectations for patient involvement in the selection process also varied greatly among and between patients and providers. We identify specific attributes of ART that are decision-relevant to patients and providers, describe heterogeneity of their relative importance, and note variable perceptions of shared decision making. Individualizing ART will require greater investment in understanding an individual patient's preferences, including her/his desire to participate in shared decision making.

Keywords: HIV/AIDS, mixed methods, patient preferences, provider preferences, antiretroviral therapy, shared decision making

Introduction

IN THE UNITED STATES ALONE, ~1 million people are living with HIV infection.¹ Since the advent of highly active combination antiretroviral therapy (ART) nearly two decades ago, HIV infection has been transformed from a nearly universally fatal illness into a life-long manageable disease. The number of effective and well-tolerated therapeutic options has increased dramatically over the past two decades. As insurance options change, more generic formulations

become available, and new dosing and administration options are developed, there is even greater opportunity for providers and patients to engage in shared decision making for ART.

As of October 2017, 26 different treatment options were classified as “recommended” initial regimens (11 recommended for most people with HIV; 15 recommended in certain clinical situations) by the Department of Health and Human Services Guidelines for Use of Antiretroviral Agents in HIV-1-infected Adults and Adolescents (DHHS Guidelines) in the United States.² Figure 1, derived from recommendations published in

¹Department of Health, Nursing, Administration, Hochschule Neubrandenburg, Neubrandenburg, Germany.

²Department of Health Services Policy and Management, Arnold School of Public Health, University of South Carolina, Columbia, South Carolina.

³Center for Health Policy and Inequalities Research, Duke Global Health Institute, Duke University, Durham, North Carolina.

⁴Department of Medicine, Division of Infectious Diseases, Duke University Medical Center, Durham, North Carolina.

FIG. 1. Changes in treatment recommendations of regimens (2009–2017). A = strong recommendation; B = moderate recommendation; C = optional recommendation; D = regimens not yet available; E = regimens removed; Different colors indicate the classification of regimens (level of recommendation or availability). Changes of two or more regimens are represented by curved lines. To ensure clarity and comprehensibility changes of just one regimen are not shown with separate lines; Data extracted from recommendations published in the 2009–2017 DHHS Guidelines, retrieved from <https://aidsinfo.nih.gov/guidelines/archive/adult-and-adolescent-guidelines>. (Color image can be found at www.liebertonline.com/apc.)

the DHHS Guidelines from 2009 to 2017, highlights the dynamic changes in treatment recommendations by strength of endorsement and availability of regimens spanning 9 years. Each treatment option combines a unique set of characteristics that different patients may value differently.

The primary drivers for a specific antiretroviral regimen should be both clinically informed and patient oriented. Key clinical variables include a given patient's CD4 lymphocyte count, HIV RNA level, the presence of coinfections (such as hepatitis B) and comorbidities (such as heart disease or pregnancy), the use of certain concomitant medications, antiretroviral resistance testing, and the patient's HLA-B*5701 status.² To date, several studies have described patient perceptions of ART in terms of quality of life, adverse effects, impact of treatment on health privacy concerns, and preferences for complementary or alternative medicines among others,^{3–8} but relatively little work has focused on how patients and their providers value specific ART attributes that are patient relevant, some of which are associated with HIV medication adherence.^{9,10}

Using qualitative methods and ranking exercises, we sought to determine key drivers of patient ART preferences, their desire to be involved in ART decision making, and the interplay between the clinical decision-making process of HIV providers and regimen-specific characteristics that are particularly important to patients.

Methods

Ethics statement

The study protocol was approved by the Institutional Review Board of Duke University Health System. Informed consent was obtained from all participants.

Methods overview

Mixed methods were used to develop a comprehensive understanding of the range of attributes of ART that providers and patients consider important in selecting regimens; to probe tradeoffs that patients are willing to make if given opportunity to participate in ART selection; and to explore attitudes of providers and patients toward shared decision making. Qualitative interview guides for provider and patient interviews were developed based on literature reviews and relevant package labeling information for recommended antiretroviral regimen (Table 1). In-depth interviews (IDIs) with HIV providers and patients were conducted to probe the importance of a wide range of antiretroviral characteristics, using a combination of open and closed questions. Providers were asked about their occupation, professional experience, specific patient population cared for, and patient involvement in ART decision-making processes. Supplemental surveys for patients participating in IDIs contained questions on sociodemographic variables, HIV history and ART treatment experiences, and patient involvement in ART decision making. Ranking tasks employing card sets, which were informed by the qualitative data, elicited the relative importance of diverse ART attributes for decision making. To better understand the importance of specific ART attributes in relation to each other, patients were asked to perform tradeoff tasks using monetary amounts. Following a triangulation design approach,^{11,12} qualitative and quantitative methods were applied and integrated to substantiate the results.

Characterization of variables

Potential decision-relevant variables derived from the literature were grouped into categories and characterized with

TABLE 1. CONTENT OF DATA COLLECTION

	<i>Provider interviews</i>	<i>Patient interviews</i>
IDI themes	Decision-making process Which regimens are considered and why? Medical and personal information that informs the treatment decision Shared decision making	Decision-making process through a hypothetical scenario: “Imagine your current drugs will not be produced anymore. What would be important for your decision on another medication?” Administration characteristics Side effects Long-term effects Shared decision making
Survey content	Profession Experience Patient populations cared for Patient involvement	Sociodemographic information HIV history and treatment Patient involvement
Ranking tasks	ART administration characteristics Side effects Long-term effects	ART administration characteristics Side effects Long-term effects

ART, antiretroviral therapy; IDI, in-depth interview.

respect to their relevance for treatment decisions by patients versus providers. Some variables were judged to be primarily relevant to patient considerations; others were deemed more important to the provider decision-making process; while some were viewed as overlapping (Fig. 2). As this study's aim was to facilitate increased patient participation in ART shared decision making, primarily clinically oriented categories (e.g., HLA-B*5701 status, CD4-cell count, HIV RNA levels, antiretroviral resistance) were excluded from the exploration of patient preferences.

Recruitment and compensation

Provider and patient participants were recruited from the Duke Infectious Diseases Clinic, Durham, North Carolina. HIV care providers were recruited by study personnel. Nontrainee healthcare providers who cared for HIV-infected

patients on a regular basis were eligible to participate. Patient participants were eligible if they were HIV infected, 18 years of age or older, and on ART. Patients were recruited by their attending physician, word of mouth, and clinic advertisements, and were compensated 50 US dollars.

Implementation of interviews and ranking tasks

The study took place between March 2016 and May 2017 at Duke University in Durham, North Carolina. Interviews were conducted in English by members of the research team. Provider interviews lasted about 30 min and patient interviews took about 90 min.

Interviews with patients were audiorecorded and transcribed verbatim. Transcripts were adjusted for dialect or shortcut articulations.¹³ Accuracy was verified through spot checks. Contemporaneous notes taken from interviews with

FIG. 2. Variables influencing antiretroviral treatment selection. (Color image can be found at www.liebertonline.com/apc.)

at least two observers were reviewed and analyzed separately. Patient and provider interviews were analyzed separately.

The relative importance of diverse treatment attributes was elicited using ranking tasks, implemented either on paper (for HIV providers) or using card sets (for patients). The set of options in the ranking tasks differed for patients and providers. Patients were asked to exclude unimportant attributes from their set of attributes. After the exclusion of “unimportant” features, each patient ranked the remaining items in order of importance.

Qualitative analysis

Interview transcripts were coded in NVivo 11 qualitative data analysis Software (QSR International Pty Ltd., version 11) using direct content analysis,^{13,14} which combines validation and extension of the decision model by allowing an incomplete and growing coding frame. While predetermined codes underlying the content analysis process were derived from the literature review, the coding scheme was updated in the coding process to capture all relevant information across interviews.^{13,14} Fifty-four codes, including adverse events, medical history, medication characteristics, and aspects of decision making were used.

Quantitative analysis

Quantitative data were analyzed using Stata SE 13 software (StataCorp). Descriptive statistics were used to analyze the sociodemographic characteristics of participants. The qualitative analysis of interview notes and transcripts was complemented by counts of the number of participants mentioning individual attributes, based on the notion that attributes mentioned by a larger number of participants were more important in the decision-making process.¹⁵

Ranking results were analyzed through count analysis. The total number of ranks varied across domains (side effects, long-term effects, administration characteristics), and across participants due to the patient-specific exclusion of unimportant attributes. To aggregate rankings across participants, individual ranks were converted to scores (ranging from 0 for excluded attributes to the total number of attributes evaluated in each domain) and scores were summed across participants.

Results

Participant characteristics

IDIs were conducted with 28 participants, including 16 patients and 12 healthcare providers. Ranking tasks were conducted with 26 patients, including 6 patient in-depth interview (PIDI) participants and a convenience sample of 20 patients who were added to increase the robustness of the results of ranking exercises. The combined patient sample ($N=36$) included 22 males and 14 females, with a mean age of 50.7 years (range, 26–71 years). All patient participants were on ART at the time of the interview; the average duration on ART was 14.8 years. Healthcare providers included 8 Infectious Disease Physicians, two social workers, one pharmacist, and one physician assistant. On average, participating providers had 15.5 years (range, 2–31 years) of professional experience.

Patient results

In the qualitative analysis of PIDIs, a variety of characteristics of ART emerged as influencing HIV treatment decisions. The majority of characteristics could be assigned to one of four categories.

Category 1: administration characteristics. Six attributes were identified in this domain, including drug interactions, taste, food requirements, mode of administration, pill size, and storage. Out of 16 patients interviewed, 14 mentioned at least 1 attribute of that category.

Four participants reported drug interactions in their medical history and highlighted the importance to not only check for interactions with HIV medicines, but also for medicines for comorbidities. Unpleasant drug taste was mentioned as important by two participants. A female respondent said:

“Some pills have an aftertaste once you swallow it and it can be a severe case to the point where you just do not want to take it.” (PIDI-09)

Some patients (6 out of 16) reported problems integrating intake requirements into their daily life. Some patients’ schedules did not allow them to take their medications with a full meal of a certain number of calories.

“You’re supposed to take that with a meal [... but] I never eat dinner at the same time. It’s just, it’s kind of an inconvenience.” (PIDI-14)

Food requirements were unimportant for other participants; they reported developing a habit of taking medicines and had no difficulties managing a food requirement.

Regarding mode of administration, five respondents stated that they would prefer medicines in the form of a liquid, capsule, or injection to either avoid swallowing pills or to lower the intake frequency with an injection once a week or month. Two participants considered pill size to be important, due to problems swallowing big pills. However, another participant reported being able to adjust to taking big pills.

Category 2: dosing. The second category comprises dosing frequency, intake time, and number of pills. In total, 13 out of 16 participants highlighted the importance of at least 1 of those attributes; 6 stressed the lack of importance of at least 1 attribute. The number of pills and dosing frequency seemed to be closely connected, since many patient participants spoke of them jointly. Single tablet regimens were generally preferred. One male patient said:

“One a day. That’s a lovely thing to have to do.” (PIDI-04)

However, dosing was less important than other attributes:

“One of the main things I would require is for that medicine to also be like one tablet a day, but the amount of that new med is not as important as what it brings, you know, what it has to offer.” (PIDI-11)

Category 3: long-term effects. Long-term effects included those that appear after taking a medication for some years and can be traced back to the HIV medication. From a total of 16 patients, 12 were concerned about at least one of the following long-term effects: decrease in bone density, brain effects, increase in cholesterol, fat redistribution, heart

problems, kidney problems, or liver problems. A female patient stated:

“I wouldn’t want it to interfere with my organs and that’s my concern about HIV meds or any long-term meds that I’m prescribed for ongoing period of time [...] I would rather be on herbal drugs than to lose my kidneys and liver.” (PIDI-11)

Category 4: side effects. Side effects included symptoms that appear in timely conjunction with medication intake. Diarrhea, difficulty thinking, dizziness, dream anomalies, fatigue, headaches, nausea, neurologic symptoms, night sweats, pneumonia, problems with bones and joints, psychological problems, sleep problems, stomach problems, vision problems, vomiting, and weight changes were mentioned in patient interviews. Out of 16 patients, 14 considered these as important, 4 mentioned side effects as not important or that they were manageable:

“If [...] this is a medicine that I have to take for better quality of health and it interrupts my sleep for any period of time it wouldn’t be acceptable. I couldn’t tolerate it” (PIDI-11).
 “Dizziness is a problem. I worry about falling.” (PIDI-15)
 “You start to learn okay, [if] I know that the diarrhea is going to hit two hours after I take my meds then I’m going to prepare for it.” (PIDI-14)

Other considerations: efficacy, privacy, and out-of-pocket costs. Out of 16 patient participants, 6 named efficacy of a medicine as an important aspect of HIV treatment decisions. Patients care about laboratory markers of their disease state, such as HIV RNA levels and the CD4-lymphocyte counts. Asked about what matters most, a male patient said:

“Well, first off of course would be the efficacy of the medication, what its track record is and everything.” (PIDI-07)

Privacy and avoiding inadvertent disclosure of HIV status was important to 4 and not important to 2 out of 16 participants.

“I have to hide [the medicines] back in my closet, you know what I mean, so that nobody—not until I get ready to tell them.” (PIDI-03)
 “I’ve always been an outspoken person when it came to my HIV whether it is in the community, whether it is with my family, whether it is with my friends, so I have never been sheltered as far as you know being hush hush about it.” (PIDI-09)

Medication cost was a topic named by 12 out of 16 participants. Even though respondents did not report current problems in paying for their medication, they considered out-of-pocket cost an important factor in HIV treatment decisions. One female participant stated:

“If I had to pay for the medicine myself, I’d probably be dead. [...] Because I couldn’t afford it.” (PIDI-05)

Table 2 shows the number of patients naming specific attributes. Since patients could mention attributes as either *important* or *not important*, counts of patients mentioning an attribute are presented differentiated depending on the content.

Tradeoffs. In tradeoff exercises, substantial variation was observed in the importance of the categories stated above (administration characteristics, dosing, long-term effects, and side effects). Dosing was named by most patients in PIDIs. However, when participants were asked to make tradeoffs

TABLE 2. NUMBER OF PATIENT PARTICIPANTS MENTIONING SPECIFIC ATTRIBUTES OF ANTIRETROVIRAL THERAPY (N= 16)

Codes	No. of patients mentioning the attribute	
	Important	Not important
No. of pills ^a	12	4
Health or physical effects	11	2
Out-of-pocket cost	11	
Dosing frequency ^a	9	3
Kidney problems	8	
Liver problems	8	
Efficacy	6	
Food requirements	6	1
Heart problems	6	
Nausea	6	
Neurologic symptoms	6	
Diarrhea ^a	5	2
Mode of administration	5	
Stomach problems	5	
Weight changes	5	1
Dizziness	4	
Drug interactions	4	
Fat redistribution	4	
Privacy	4	2
Sleep problems	4	
Bone density decrease	3	
Brain effects	3	
Dream anomalies	3	1
Fatigue	3	
Psychological problems	3	

^aContradictory statements by the same participant were counted in both columns (diarrhea: 1, dosing frequency: 3, number of pills: 3); Drug taste, headaches, intake time, night sweats, pill size, problems with bones and joints, resistance, storage, vomiting, cholesterol increase, difficulty thinking, and vision problems were mentioned by fewer than three participants.

between side effects or long-term effects and pill burden, most participants were willing to accept a higher pill burden in exchange for reduced side or long-term effects.

[Interviewer:] “Let’s assume [...] you would go to a regimen which means twenty-seven tablets but there would be not such a high risk for having liver problems and your renal system would be great, would you do it?”

[Subject:] “I would try it, yes.” (PIDI-14)

[Interviewer:] “So there’s a drug which would cause dizziness, but you could go down to one tablet in the morning, and there’s a drug which doesn’t cause dizziness but you would have to take two tablets two times a day.”

[Subject:] “Two tablets two times a day. I probably would go with the two tablets twice a day.” (PIDI-15)

In other tradeoff exercises, participants were asked which amount of money they would be willing to pay for a new drug with less side or long-term effects. Participants’ willingness to pay differed between patients and in relation to their perceived importance of the attribute.

[Interviewer:] “Let’s say there [...] was] some protein detected [in your urine] this time and you were to change and suddenly there would be an increase in the copayment [...] to \$100.00 by switching to one that doesn’t [cause kidney issues ...]. Would you pay it?”

[Subject:] “Yes.”
 [Interviewer:] “Yes? \$100.00?”
 [Subject:] “I’m pretty sure I would.” (PIDI-16)
 [Interviewer:] “Let’s assume your drug actually results in sleeping problems. You go to your doctor [...]. He says well you know, there’s something else but co-pays are real expensive. We’ve got to have some co-pay. \$100.00?”
 [Subject:] “Yes.”
 [Interviewer:] “\$150.00?”
 [Subject:] “Yes.”
 [Interviewer:] “\$200.00? \$250.00?”
 [Subject:] “My stopping point would be 200.” (PIDI-13)

Patient involvement, relationships with providers, and shared decision making. Patients mentioned the importance of a good relationship and open communication with their HIV provider. Participants highlighted in the PIDIs that focusing on laboratory values is not enough for a satisfactory HIV treatment:

“I am not my diagnosis. I am somebody. [...] So I think he is starting to understand that, that I need more than “your levels are fine.” He literally turns the screen and scrolls down and shows me the levels and recent tests and what he wants and what he thinks how we should move forward.” (PIDI-06)

In general, patients reported a good relationship and communication in the interviews:

“You know, I would talk to my doctor, what’s his experience with the medication and what he knows about the medication [...]. I would pump my doctor for information, what he knows [...], how an adverse reaction relates to the majority of people on this medication as opposed to [a] small group.” (PIDI-07)
 “And fortunately that I have an excellent communication with my doctor because if I have an issue with home or something comes up I can email him and I will hear back from him immediately. So that helps a lot to have good communication.” (PIDI-04)

Involvement in treatment decisions was reported as an important factor in PIDIs; however, the desired degree of involvement differed greatly across participants. While a majority of patients preferred some involvement, the spectrum of desired participation in treatment decisions ranged from the patient being the final decision maker to complete paternalism.

“Ultimately it is that patient’s decision but I take the advice of what my doctor offers.” (PIDI-02)
 “Like I said, I did it because the doctor prescribed them for me. [...] And I figured she would know what was best for me. She’s the doctor and I’m not. [...] So whatever she prescribed, I took. [...] Just as simple as that, you know.” (PIDI-13)

Patient rankings

Patients were asked to rank the importance of various administration characteristics, long-term effects, and possible side effects. The set of administration characteristics also included dosing attributes. (Note: the division into four different categories—as stated above—emerged later in the study during qualitative analysis.) Figure 3 shows the aggregated results of the ranking tasks with patients. The left side shows the complete rankings, whereas the right side shows the distribution of the top 3 ranks. The bars indicate how often an attribute was ranked first, second, or third. The number of ranks varied due to

ties on some ranks (e.g., two first ranks led to skipping the second rank) and incomplete rankings (i.e., patients were asked to exclude unimportant attributes before the ranking).

Among administration characteristics (panel A), *insurance restrictions* were ranked first, followed by *out-of-pocket costs* (rank 2), *drug interactions* (rank 3), and dosing characteristics (ranks 4 and 5). *Number of pill bottles* was ranked last (rank 12), after *catch-up option* (possibility to take the medication some hours later, if forgotten; rank 11), and *intake restrictions* (rank 10). Among long-term effects (panel B), patients ranked *heart problems* (rank 1), *kidney problems* (rank 2), and *liver problems* (rank 3) highest, and *bone density decrease* and *changes in physical appearance* (both on rank 5) and *cholesterol increase in your blood* (rank 7) lowest. Among side effects (panel C), patients considered *depression or feeling very sad* and *issues with muscles* (both on rank 1), and *issues with bones* (rank 3) most important. The lowest importance ranks were taken by *reversible jaundice* (rank 16), *weight loss* (rank 17), and *flatulence* (rank 18). Across the three categories, the results suggest a large degree of preference heterogeneity across patients.

Provider results

Interviews with healthcare providers revealed different perceptions of the optimal level of patient involvement. Among the 12 providers, the share of patients estimated to prefer paternalism ranged from 1% to 90%. Providers had diverse views on their own role and the role of the patient in the ART decision-making process.

“I don’t like to be that type of provider. So I try to get in and ask patients to take some ownership.” (IDI-10)
 “Most patients don’t want to be saddled by burden of decision. They are intimidated because they are not used to making decisions like this. They are scared. They want the best and they want you to give it to them.” (IDI-11)

Two providers suspected a connection of a preference for paternalism with being younger, being diagnosed more recently, and having lower socioeconomic status.

Provider rankings

Figure 4 shows the aggregated results of the ranking tasks with providers. As above, the left side shows the complete ranking, whereas the right side shows the distribution of the three highest ranks. The bars indicate how often an attribute was ranked first, second, and third. The total number of ranks differs due to ties on some ranks (e.g., two first ranks led to skipping the second rank) and incomplete rankings.

Among administration characteristics (panel A), providers considered *daily dosing frequency* (rank 1), *number of pills* (rank 2), and *drug interaction* (rank 3) most important. *Number of pill bottles* (rank 7), *intake restrictions* (rank 6), and *pill size* (rank 5) were considered the least important attributes. Among long-term effects (panel B), *fat redistribution* was ranked first, followed by *renal effects* (rank 2), and *hepatic effects* and *cardiac effects* (both on rank 3). *Lipid effects* ranked last (rank 6), after *bone effects* (rank 5). Among side effects (panel C), providers considered *nausea* (rank 1), *diarrhea* (rank 2), and *neurological/psychological effects* (rank 3) most important. *Reversible jaundice* (rank 5),

FIG. 3. Patients' rankings of treatment attributes and distribution of the highest ranks ($N=26$). Notes: Total number of ranks varies due to ties and exclusion of nonimportant characteristics. Individual ranks were converted to scores (ranging from 0 for excluded attributes to the total number of attributes evaluated in each domain) and scores were summed across participants. (Color image can be found at www.liebertonline.com/apc.)

musculoskeletal effects (rank 6), and *other gastrointestinal effects* (rank 7) were ranked lowest.

Discussion

This study identified a wide range of characteristics of HIV ART that are important to patients, and thus relevant to the ART decision-making process by patients and providers. Consistent with prior studies,^{5,6} the results show a general concordance between patients and providers with regard to major decision-relevant categories of HIV medication, namely long-term effects, side effects, dosing, administration characteristics, and cost. However, while the categories were broadly consistent between patients and providers, the specifications varied among and between the two groups and the degree of concordance differed across categories. An example for discordance among long-term effects is the relative importance of fat redistribution/changes in physical appearance; this attribute

was ranked most important among providers' consideration of patient preferences, and penultimate by patients. Substantial differences were also observed in the importance rankings of specific side effects. The most concerning side effect overall for patients, depression or feeling very sad, was only in the middle of the provider rankings. Providers' top two ranks (nausea and diarrhea) were much lower in the patient ranking (ranks 8 and 9). Administration characteristics were ranked broadly similar across groups, except for food requirements, which were ranked higher by providers than patients. Finally, three-quarters of the patient participants named medication cost as an issue, and we note that others recently found that a significant minority of HIV-infected patients report financial barriers to accessing ART.¹⁶

Involvement in treatment decisions, facilitated by open communication and a good relationship with one's HIV provider, was important to patients living with HIV. This finding is in keeping with results of several other studies.^{17–20}

FIG. 4. Providers' rankings of treatment attributes and distribution of the highest ranks ($N=12$). Notes: Total number of ranks varies due to ties and exclusion of nonimportant characteristics. Individual ranks were converted to scores (ranging from 0 for excluded attributes to the total number of attributes evaluated in each domain) and scores were summed across participants. (Color image can be found at www.liebertonline.com/apc.)

Patients' preferences for involvement ranged from the provider making decisions for the patients, to providers and patients being involved equally in the decision, to patients making the decision.^{21,22} Providers' estimates of the share of their patients with a paternalism preference ranged from 1% to 90%. Another study found that almost 80% of patients living with HIV preferred some measure of a shared role in the treatment decision processes.²³ Improving communication and developing tools for conveying risks and assessing patients' responses to such risks hold promise for incorporating patients' priorities, when medically appropriate, in the selection of ART regimens. Moreover, greater participation by patients in the selection of ART may lead to greater involvement in other aspects of their healthcare, such as cardiovascular disease risk management, which has become increasingly important for patients living with HIV.²⁴

Overall, the results of this study highlight substantial preference heterogeneity among and between patients and providers. A tool that assesses patient preferences could potentially be incorporated into a shared decision-making process to optimize patient-centered treatment decisions. The widely varying valuations of individual attributes, however, suggest the need for a highly flexible tool to assess the heterogeneous preferences in this population.

The study is subject to several limitations. First, direct content analysis was used for the coding process by one researcher, which may be considered a restrictive coding method, due to the possible risk of one-way-thinking as described in the literature.^{14,15} Second, the set of attributes included in ranking tasks was prespecified and varied between providers and patients. The importance of different attributes may have been influenced by the sets of options considered by participants.

Howard and Seth²⁵ describe the so-called evoked set, containing contemplated alternatives, as a subset of options one is aware of (awareness set). Furthermore, the number of alternatives available (here preference-relevant characteristics of ART) may be even bigger than the options in the awareness set.^{25,26} Third, the assumption of concordance between the number of participants naming an attribute and attribute importance may be restrictive. For example, results of tradeoff decisions appear to contradict the importance of dosing characteristics derived from the frequency of naming individual attributes. Finally, the small sample size could limit representativeness and generalizability of findings. Sociodemographic characteristics of the participants, such as gender and race, in relation to patients' preferences were not included in this analysis, although others have shown that these characteristics are associated with ART treatment continuity.²⁷ These limitations suggest that the aggregated ranks should be interpreted with caution and that the tradeoffs patients are willing to make should be formally evaluated. A discrete choice experiment would allow for presentation of combinations of several attributes with different importance weights and thus the elicitation of more robust data on patient preferences.²⁸

This study identifies a large number of preference-relevant characteristics of HIV medications. These characteristics broadly fall into five categories: dosing, administration characteristics, long-term effects, side effects, and other considerations. Moreover, these findings suggest considerable heterogeneity in preferences across patients, in providers' perception of patient preferences, and in patients' desired level of involvement in HIV treatment decisions. While the results support the need for a tool to elicit individual patients' preferences and incorporate them into the shared decision-making

process, such a tool must be highly flexible to accommodate the large heterogeneity in preferences.

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Address correspondence to:
Nathan Thielman, MD, MPH
Division of Infectious Diseases
Duke University Medical Center
201 Trent Hall, Trent Drive
Durham, NC 27708

E-mail: n.thielman@duke.edu