

Reasons for Accepting and Declining Free HIV Testing and Counseling Among Young African American Women Living in Disadvantaged Southern Urban Communities

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Abstract

Advancing HIV prevention and treatment among at-risk Southern communities of color requires understanding why voluntary HIV testing is accepted or declined. Reasons for testing decisions were investigated among young African American women ($n=223$, mean age=20.4 years) recruited from disadvantaged areas in a Southern US city. A free HIV test was offered following field interviews that assessed HIV risk behaviors and personal and social network characteristics; 69.1% accepted testing, and all were seronegative. After their decision, participants rated reasons for their choice, which were factor analyzed. A four-factor solution showed that test acceptance was related to (1) current sexual relationships and HIV risk concerns, (2) knowledge of HIV medical treatment benefits, (3) awareness of persons living with HIV, and (4) health protection and HIV test convenience. A three-factor solution showed that test refusal was related to (1) negative consequences of a positive test and privacy concerns, (2) low perception of HIV risk, and (3) anticipated social rejection if the test was positive. Comparisons of factor-based average item scores showed that health protection/HIV test convenience was rated as most influential in test acceptance decisions, whereas low perception of HIV risks was rated as most influential in test rejection decisions. The findings suggest that test acceptance can be promoted by offering free, convenient HIV testing as a health check in a testing context that assesses and provides feedback about participants' HIV risk levels.

Keywords: HIV testing, African Americans, women, emerging adults, HIV treatment cascade

Introduction

COMPARED TO OTHER REGIONS of the United States, Southern states carry a higher burden of HIV infection, illness, and death, particularly among African Americans.^{1,2} African Americans were 54% of all Southern persons living with HIV (PLWH) in 2014, and more than two-thirds (69%) of Southern women living with HIV were African American.² Moreover, Southerners have worse outcomes at all points on the HIV treatment cascade or continuum of care³ that spans initial disease detection, engagement and retention in care, and successful viral suppression. Improving all steps along the continuum is thus a critical need in Southern communities of color, particularly among African American women. Social, economic, racial, and healthcare infrastruc-

ture barriers to providing comprehensive HIV/AIDS services in the South have been well documented.⁴⁻⁶ However, much less is known about influences on specific behavioral steps involved in improving engagement and outcomes along the HIV continuum of care.

This information is needed to promote positive transitions along the continuum, starting with reaching at-risk individuals and groups for HIV testing as part of the comprehensive "Seek-Test-Treat-Retain" (STTR) strategy for HIV prevention and treatment.⁷ This need is especially acute for community-dwelling African American young women who are seronegative and engaging in HIV risk behaviors but are unlikely to seek out HIV testing specifically or use healthcare services generally where testing may be offered. They are a key HIV prevention target group, but have been understudied

in research on barriers to and incentives for HIV testing in community settings, which has tended to focus persons who have already been diagnosed with HIV.^{8–10}

Community-based testing programs have received some recent empirical attention using qualitative focus group methods that offered preliminary evidence about influences on HIV testing and related care-seeking among African American women.¹¹ Stigma, concerns about privacy, access issues, emotional support, and assurances about the potential to live a healthy life with HIV were common themes. Further development of culturally sensitive community-based testing programs for this risk group would benefit from systematic investigation of variables established as determinants of medical help-seeking in several relevant disciplines, in addition to these qualitative HIV-related findings.

Specifically, accepting HIV testing is a form of medical help-seeking and should be influenced by the range of help-seeking barriers and incentives identified in the medical sociology,^{12–14} psychology,^{15,16} health economic,^{17,18} and behavioral economic¹⁹ literatures. Medical sociology findings indicate that help-seeking is a social process influenced by social network norms, practices, feedback, stigma, and meeting the demands of everyday roles. Health and behavioral economic research directs attention toward creating conditions to stimulate “demand” for HIV testing by making it affordable and accessible with minimal delays to receipt of services. Psychological studies point to the role of individuals’ cognitions and affective states that are proximal to health-related decisions and behaviors (e.g., knowledge, risk perception, and motivation).

Collectively, this multi-disciplinary literature suggests that optimal conditions for HIV test acceptance would involve free testing in a private, supportive context with minimal delays to receiving test results and rapid referral for care if needed. Using a community-based sample of young African American women recruited from disadvantaged areas in a Southern US city, we created such HIV testing conditions to investigate personal, social, and health-related reasons for accepting or declining voluntary HIV testing. Participants were free to accept or decline testing; 69.1% accepted it, and all were seronegative.

Immediately following their decision, participants who accepted testing rated incentives, and those who declined testing rated barriers that were culled from the relevant medical sociology, psychology, health, and behavioral economic literatures.^{20–25} The quantitative rating scales ensured that participants were presented with the entire range of potential influences, which minimized the influence of cognitive biases or social dynamics that can operate in focus group data collection. Surveying reasons immediately after observing HIV test choices was a methodological improvement over earlier retrospective assessments of testing behavior over variable or indeterminate intervals.¹⁵ This quantitative research approach builds on earlier HIV studies and can help advance the STTR strategy by guiding the creation of community testing contexts that are responsive to the likely mix of incentives and barriers.

Participants’ ratings of reasons to accept or decline HIV testing were examined using exploratory factor analysis (EFA) to identify the dimensions of reasons for testing decisions. Given the inherently social nature of HIV risk transmission, we predicted that a new sexual relationship or concerns about a sexual partner’s fidelity should promote test acceptance, whereas anticipated social rejection for a positive test and

concerns about keeping results private should deter testing. We further predicted that benefits of early HIV treatment and HIV testing for health protection would emerge as reasons for accepting testing, whereas low perceived HIV risk would emerge as a reason for declining testing.

Methods

Sample recruitment

African American females ages 15–25 years ($n=223$) from disadvantaged areas of a Southern US city were recruited as a supplemental sample to a larger parent study²⁶ of risk and protective factors for substance misuse, HIV/AIDS, and other health risk behaviors in male and female African American emerging adults. Although emerging adulthood is often defined as ranging from 18 to 25 years,²⁷ the 15- to 25-year age range was chosen because the target population often experiences more health risks and economic pressures to transition to adult roles quickly compared to their higher socioeconomic status peers.^{28,29} As in the parent study, the supplemental sample was recruited using respondent-driven sampling (RDS),^{30,31} a peer-driven method suitable for recruiting hard-to-reach risk groups such as community-dwelling emerging adults. From April 2012 to September 2014, initial “seed” participants from the target group recruited peers, who then recruited their peers in an iterative process until the sample was obtained. The research received university Institutional Review Board approval and a federal Certificate of Confidentiality and adhered to Strengthening the Reporting of Observational Studies in Epidemiology guidelines.³²

Procedures

After obtaining participants’ written informed consent, staff members similar in age or race to the target population conducted 1.5- to 2.0-h structured field interviews in safe, private community locations that assessed personal characteristics and circumstances, substance use [Alcohol, Smoking, and Substance Involvement Screening Test (ASSIST v3.0)],³³ sexual behaviors (Youth Risk Behavior Survey),³⁴ behavioral impulsivity (monetary delay discounting task),³⁵ and social network feedback about health risk and protective behaviors (expanded Norbeck Social Support Questionnaire).³⁶ These measures and findings are described in earlier articles from the parent study.^{26,37–40} Following the interview assessment, participants received instruction on how to recruit up to three peers “like yourself” using coupons with unique numbers. Peers could use the coupons later to enroll in the study, which afforded privacy of choice whether to participate.

Interviewers then offered participants free voluntary HIV counseling and testing (OraQuick) with guaranteed referral to medical care if results were preliminary positive. After making their choice, participants in the present sample answered structured questions described below about why they either accepted or declined testing. This kept the duration of remaining participation similar regardless of test choice. Participants received \$30 gift cards for their interviews and \$15 for each enrolled network member (up to three maximum).

Measures

Reasons for accepting or declining HIV testing were identified from the literatures summarized earlier.^{20–25} Initial

candidate items were reviewed by an experienced health educator who worked with PLWH who were patients in a comprehensive HIV/AIDS health center in Alabama for content, culturally appropriate language, and educational level (eighth grade). Items were revised accordingly, and redundancies in candidate items were eliminated. The final form included 20 reasons for HIV test acceptance and 15 reasons for test refusal. Internal consistency of both sets of reasons was excellent with Cronbach's α of 0.82 and 0.74 for acceptance and refusal reasons, respectively. Participants rated how much each reason influenced their testing decision on 5-point Likert scales (1 = very/most important reason to 5 = not a reason at all).

Data analyses

Of the 223 participants recruited, 154 accepted the HIV test, and 69 declined. For EFA, participants who had missing values on any items were excluded, resulting in an analysis sample of 207. Table 1 presents the characteristics of the analysis sample. Due to unexpected funding cuts, recruitment ended before a sufficiently large sample was recruited to support standard RDS analysis procedures.^{41,42} Therefore, the data were analyzed without weights based on network size or other adjustments recommended for RDS-generated samples.

TABLE 1. SAMPLE DEMOGRAPHIC CHARACTERISTICS AND DESCRIPTIVE STATISTICS

<i>Study variables</i>	<i>Frequencies/means</i>
Demographic characteristics (frequencies and %)	
High school completed ^a	177 (85.5)
Average grades ^b	
Mostly As	37 (17.9)
Mostly Bs	124 (59.9)
Mostly Cs or lower	46 (22.2)
Employed ^c	111 (53.6)
Receipt of public assistance	152 (73.4)
Married	21 (10.1)
Have children	57 (27.5)
Age in years (mean and SD)	20.4 (2.5)
HIV test decisions (frequency and %)	
Accepted	143 (69.1)
Declined	64 (30.9)
Health risk behaviors	
Sum of risky sexual behaviors ^d (mean and SD)	1.2 (1.2)
ASSIST GCR substance involvement score ^e (mean and SD)	20.6 (18.5)

Note: ASSIST GCR subscale (range=0–280).

^aParticipants were in high school or earned high school diploma or GED.

^bAverage grades in the last 2 years in school.

^cEmployment resulting in at least weekly pay.

^dSum of seven binary measures of risky sexual behaviors (i.e., first sexual intercourse before age 16, not using a condom during the last sex, substance use during the last sex, having two or more sexual partners in the past 90 days, sex with injection drug users, using no birth control, and sex involving transaction of money).

^eUse of specific substances and global risk scores based on ASSIST reports of lifetime substance use; the GCR subscale also assessed lifetime network concerns about substance use, failed quit attempts, and injection drug use.

ASSIST, Alcohol, Smoking, and Substance Involvement Screening Test; GCR, Global Continuum of Risk; GED, general educational development; SD, standard deviation.

Separate EFAs were conducted in SPSS for ratings of reasons for test acceptance or refusal. Principal Axis Factoring (PAF) was used, as our goal was to understand the underlying dimensions of the reasons for accepting or declining HIV testing based on their shared variances, and PAF can be used under the violation of normality assumption.⁴³ Correlations among factors were allowed by promax oblique rotation. The number of factors was determined based on factor eigenvalues and scree plots. Four-factor solutions were estimated with 143 participants who accepted HIV testing and rated 20 acceptance reasons; three-factor solutions were estimated with 64 participants who declined HIV testing and rated 15 reasons for refusing. In both EFAs, items with low factor loadings (<0.25) were excluded, resulting in 19 acceptance reasons and 12 refusal reasons. Deleted items are reported in the notes for Tables 2 and 3. Because the number of participants who declined testing was small, this EFA was considered exploratory.

One-way analyses of variance (ANOVA) were then conducted on the factor-based average item scores (i.e., mean of the item scores relevant to each factor) separately for the four test acceptance and three test refusal factors to compare the extent to which the domains of reasons influenced participants' testing decisions. When the ANOVA was significant, Bonferroni-adjusted pairwise *t*-tests were used to examine differences among the mean scores.

Results

Tables 2 and 3 present the results of the separate EFAs conducted for the reasons for test acceptance and the reasons for test refusal. For acceptance reasons, the Kaiser–Meyer–Olkin (KMO) measure of sampling adequacy was 0.76, and Bartlett's test of sphericity was significant ($p < 0.001$), indicating that the data were appropriate for factor analysis.⁴⁴ As shown in Table 2, four factors of the test acceptance (A) reasons together accounted for 39.31% of the total variance of the items. Based on the content of factor items, the HIV test acceptance factors primarily reflected (1A) concerns about current sexual relationships and HIV risk (22.30% of variance explained), (2A) knowledge of benefits of HIV medical treatment (8.06%), (3A) awareness of PLWH (5.25%), and (4A) health protection and test convenience (3.69%).

Items measuring reasons for refusing HIV testing were adequate although not optimal for factor analysis, with a KMO of 0.53 and a significant Bartlett's test ($p < 0.001$), which is understandable considering the smaller sample size. Factors of test rejection (R) identified in the three-factor solution accounted for 52.57% of the total variance. The three factors conveyed (1R) anticipated negative consequences of a positive test result and privacy concerns (29.37% of variance explained), (2R) low perception of HIV risk (15.15%), and (3R) anticipated rejection from family, friends, and/or partner (8.05%).

The ANOVA on the factor-based average item scores for test acceptance reasons was significant, $F(3, 426) = 402.65$, $p < 0.0001$, indicating that the means for acceptance reason domains were statistically different overall. As shown in Table 4, pairwise comparisons among the acceptance factors showed that all means were significantly different from one another, with Factor 4A (health protection/test convenience) rated as more influential in acceptance decisions than any

TABLE 2. FACTOR LOADINGS FOR 19 REASONS FOR ACCEPTING HIV TESTING

<i>Reasons for accepting HIV testing (% variance explained)</i>	<i>Factor loadings</i>
Factor 1A: Current sexual relationships and HIV risk concerns (22.30%)	
I've had sex with someone who has a risk for HIV, like using needles to inject drugs, having unsafe sex, or being on the down low.	0.77
I did or am doing something risky, and I'm worried I may have gotten HIV and want it checked.	0.73
I know or suspect that my spouse or partner is having sex with other people, and I'm worried I may have gotten HIV and want it checked.	0.70
I want to start having unprotected sex with someone who insists that I get tested first.	0.39
A doctor or nurse has recommended that I get tested.	0.37
I want to get tested because I would like to start a new sexual relationship with someone.	0.35
Factor 2A: Knowledge of HIV medical treatment benefits (8.07%)	
People who test positive and get HIV treatment and stay with it can have a near normal lifespan.	0.77
If I were to test positive, I've heard the medicines used now to treat HIV are easier to take and have fewer side effects.	0.71
If you get HIV, finding out as soon as possible after you get infected means treatment can start quickly, and this leads to the best health outcomes.	0.70
When women are pregnant, treatment for HIV can stop the spread of the virus to the baby during birth.	0.49
I work in a field that may expose me to HIV.	0.48
Factor 3A: Awareness of PLWH (5.25%)	
Famous people like Magic Johnson have been treated for HIV for a very long time and seem to be well.	0.91
I saw a TV show or movie that made me think about getting tested.	0.62
I know people who have HIV, and they seem to be well.	0.31
Factor 4A: Health protection and HIV test convenience (3.69%)	
I want to protect my health and understand and control my health choices.	0.87
It's free and convenient today.	0.46
I'm pretty sure I don't have HIV, but I want a test to confirm what I believe.	0.33
I want to know my status so I can protect the health of my current or future sexual partners and not spread HIV.	0.32
I just want to be tested as a routine checkup.	0.32

Note: One item ("I need the test results for immigration purposes") was excluded in the EFA because of a low factor loading (<0.25). EFA, exploratory factor analysis; PLWH, persons living with HIV.

TABLE 3. FACTOR LOADINGS FOR 12 REASONS FOR DECLINING HIV TESTING

<i>Reasons for declining HIV testing (% variance explained)</i>	<i>Factor loadings</i>
Factor 1R: Negative consequences of a positive test and privacy concerns (29.37%)	
If I were to test positive, I don't trust doctors or nurses to keep my HIV status private.	0.85
If I were to test positive, I am worried about the State of [] having that information.	0.75
If I were to test positive, I wouldn't want to take the treatments for HIV, which I've heard are difficult to follow and have a lot of unpleasant side effects.	0.70
If I were to test positive, I am worried about being able to keep my HIV status private from people I know.	0.66
I really don't want to know my HIV status.	0.61
If I were to test positive, I wouldn't know how to get HIV health care.	0.45
If I were to test positive, I don't have the money or insurance to get HIV health care.	0.29
Factor 2R: Low perception of HIV risks (15.15%)	
I am not a member of a high risk group (e.g., men who have sex with men, injection drug users).	0.86
I consistently practice safer sex, including me or my partner always using a condom.	0.65
I don't think I'm personally at risk for having gotten infected with HIV.	0.64
Factor 3R: Anticipated social rejection if tested positive (8.05%)	
If I were to test positive, I would have to tell my partner, and s/he may reject me or judge me harshly.	0.85
If I were to test positive, my family or friends may reject me or judge me harshly.	0.76

Note: Three items with low factor loadings (<0.25) were excluded in EFA: (1) "I have been tested before, and it was negative"; (2) "I am tested regularly as part of my job"; and (3) "I give blood regularly/recently and get tested when I do." EFA, exploratory factor analysis.

TABLE 4. COMPARISONS OF FACTOR-BASED MEAN ITEM SCORES OF PARTICIPANTS' REASONS FOR ACCEPTING OR REFUSING FREE HIV TESTING

<i>HIV testing decision factors</i>	<i>Mean</i>	<i>SD</i>
Reasons for accepting HIV testing (<i>n</i> =153)		
1A: Current sexual relationship and HIV risk concerns	4.46 ^a	0.80
2A: HIV medical treatment benefits	3.34 ^b	1.14
3A: Awareness of PLWH	3.86 ^c	1.20
4A: Health protection and test convenience	1.38 ^d	0.65
Reasons for refusing HIV testing (<i>n</i> =69)		
1R: Negative consequences of a positive test and privacy concerns	4.61 ^b	0.71
2R: Low perception of HIV risks	2.94 ^a	1.56
3R: Anticipated social rejection if tested positive	4.48 ^b	1.06

Note: Items rated on 5-point scales (1=very/most important reason to 5=not a reason at all). Different superscripts indicate significantly different factor-based mean item scores in separate Bonferroni-adjusted pairwise *t*-test comparisons of acceptance and refusal factors (*p*'s<0.001).

PLWH, persons living with HIV; SD, standard deviation.

other factor. The ANOVA on the average item scores for test refusal factors also was significant, $F(2, 126)=53.39$, $p<0.0001$. Pairwise comparisons between refusal factor scores showed that Factor 2R (low perception of HIV risks) was rated as more influential in test rejection decisions than Factors 1R (negative consequences of a positive test/privacy concerns) and 3R (anticipated social rejection if tested positive), which did not differ significantly. While test refusers rated low perception of HIV risk as the more important reason for their decision, post hoc comparisons showed that they did not differ from those who accepted testing on HIV risk behaviors, including substance use as measured by the ASSIST Global Continuum of Risk scale³³ and risky sexual practices reported on the Youth Risk Behavior Survey³⁴ (e.g., no condom use during last sex, substance use before last sex, and two or more partners in past 90 days).

Discussion

Free voluntary HIV testing was offered under conditions highly conducive to accepting it. Interviewers had established rapport and spoken at length with participants about their sexual and other sensitive health behaviors, and test results were available quickly (20–30 min) with assurance of immediate referral to the local university HIV/AIDS clinic for confirmatory testing and HIV care if needed. Even under these conditions highly conducive to HIV testing, about 30% of participants declined testing, indicating the need and opportunity for improving testing circumstances, taking into account the observed mix of incentives and barriers to testing.

The EFAs of participants' ratings of the importance of reasons for their observed testing decision revealed four acceptance factors and three rejection factors that accounted for 39.31% and 52.57% of the total variance of the test acceptance (Table 2) and test rejection (Table 3) items, respectively. This indicates that the items collected from the multiple literatures on care-seeking captured some key influences on HIV testing decisions. Test acceptance was related to (1A) current sexual relationships and HIV risk

concerns, (2A) knowledge of HIV medical treatment benefits, (3A) awareness of PLWH, and (4A) health protection and HIV test convenience. In order of diminishing influence, health protection and HIV test convenience, awareness of HIV medical treatment benefits, awareness of PLWH, and current sexual relationships/HIV risk concerns were rated as important reasons for accepting testing.

Test refusal was related to (1R) negative consequences of a positive test and privacy concerns, (2R) perceived low HIV risk, and (3R) anticipated rejection from family/partner/friends if tested positive. Low perceived HIV risk was rated as more influential than the other two factors, which did not differ significantly, even though reported risk behaviors did not differ significantly between test acceptors and refusers.

Consistent with predictions, valuing HIV testing for health protection and test convenience were influential incentives, which suggests the utility of presenting HIV testing as a positive health behavior. Contrary to predictions, relationship issues were less influential, suggesting that social concerns and HIV stigma are reliable considerations, but perhaps less influential than valuing HIV testing for health protection and minimizing time and monetary costs of testing opportunities, at least in this sample of disadvantaged young women.

Also as hypothesized, the results for rejection reasons indicated that low perception of HIV risks was the primary consideration in test refusal, more so than privacy or social concerns of a positive test. Risk perception is a complex process that can be determined by actual behavior, membership in different risk groups, and social network characteristics, among other psychosocial variables,^{15,44} and perceived risk often does not align with real risk.⁴⁵ In the present study, test refusers' perception of low HIV risk was not supported by their reported risky sexual behaviors and substance involvement, which did not differ from levels reported by test acceptors. This apparent misperception supports the value of assessment and feedback aimed at closing the gap between perceived and real risk of HIV.

The findings have implications for promoting HIV testing among community-dwelling young African American women who are at risk for HIV. The study supports a comprehensive approach that (1) uses community-based social network methods to reach at-risk youths unlikely to present at clinics for HIV testing or related services; (2) offers HIV testing under convenient conditions that minimize or eliminate monetary costs or delays in test access and results, as created here in line with health and behavioral economic models of health services utilization; (3) targets inaccurate perceptions of low HIV risks for assessment and intervention; and (4) emphasizes the positive health protection afforded by HIV testing. Such a multidimensional approach to improving HIV testing rates is responsive to the observed mix of testing incentives and barriers and is not limited to a single disciplinary perspective.

Moreover, in contrast to other community-based studies that suggest the need to educate emerging adults about HIV risks and protections, at least in some contexts,^{46,47} the present sample appeared well informed about HIV disease and advances in its treatment and viewed HIV testing as a positive health behavior. Most participants were willing to accept HIV testing when it was offered to them on site without cost during a supportive confidential interaction. Taking economic contextual features into account when crafting testing programs concurs with other research with emerging adults that

suggested the value of incentivizing HIV testing with commodities of value to young people, such as money, club admission, or free drinks.⁹

Another study contribution is the empirical foundation the EFA findings provide for further psychometric development of a comprehensive questionnaire to assess HIV testing incentives and barriers. The identified factors were cohesive, generally replicated known barriers to HIV testing (e.g., privacy concerns and stigma), and provided new information about what motivates young women to get tested. Although the test refusal factors should be viewed with more caution because of the smaller sample size, the coherent structure of the identified acceptance and rejection factors suggests that the set of questionnaire items effectively measured a range of reasons for HIV testing decisions.

The study has limitations. First, the present sample lived in an urban area with a university-based Center for AIDS Research active in the community, and most had completed high school. Whether testing factors reflecting their knowledge about HIV transmission, treatment, and prevention would generalize to other samples (e.g., rural and less educated) is not known. Second, the sample size was not sufficiently large to apply standard RDS sample weighting and analysis procedures,^{41,42} making the sample potentially subject to biases related to non-random recruitment among network members. Nevertheless, the RDS data checks for the larger parent study²⁶ that used the same recruitment method in the same neighborhoods showed no evidence of recruitment bias or nonequilibrium of risk behavior distributions across recruitment waves. Third, study variables were based on verbal reports of sensitive behaviors in face-to-face interviews. To facilitate accurate reporting, strong confidentiality protections were implemented, reports of risk behaviors and events were collected using validated measures, and participants and interviewers were of similar age and/or race. Furthermore, sample risk profiles and prevalence estimates in the parent study compared favorably with matched samples from representative US national surveys.²⁶ There is no reason to expect otherwise for the supplemental sample.

With these qualifications, the findings suggested that perceived reasons for accepting or declining a free HIV test involve a mix of incentives and deterrents. These findings are informative for community-based programs to reaching at-risk groups and individuals for HIV testing, the first step in the STTR strategy⁷ aimed at improving the HIV continuum of care. This approach may enhance delivery of evidence-based interventions to promote positive transitions along the HIV care continuum, which remain critical needs in Southern women and communities of color.

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Author Disclosure Statement

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