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The Association of Provider Communication with Trust among Adults with Sickle Cell Disease

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BACKGROUND: Adults with sickle cell disease often report poor interpersonal healthcare experiences, including poor communication with providers. However, the effect of these experiences on patient trust is unknown.

OBJECTIVE: To determine the association between patient ratings of the previous quality of provider communication and current trust in the medical profession among adults with sickle cell disease.

RESEARCH DESIGN: Cross-sectional survey.

PARTICIPANTS: A total of 95 adults with sickle cell disease.

MEASUREMENTS: The four-item Provider Communication Subscale from the Consumer Assessment of Healthcare Plans and Systems Survey; The five-item Wake Forest Trust in the Medical Profession Scale.

MAIN RESULTS: Better ratings of previous provider communication were significantly associated with higher levels of trust toward the medical profession. A 10% increase in provider communication rating was associated with a 3.76% increase in trust scores ($p < 0.001$, 95% CI [1.76%, 5.76%]), adjusting for patient-level demographic, clinical, and attitudinal characteristics.

CONCLUSIONS: Poorer patient ratings of provider communication are associated with lower trust toward the medical profession among adults with sickle cell disease. Future research should examine the impact of low trust in the medical profession on clinical outcomes in this population of patients.

KEY WORDS: sickle cell disease; trust; quality of healthcare.

J Gen Intern Med 25(6):543-8

DOI: 10.1007/s11606-009-1247-7

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BACKGROUND AND OBJECTIVES

Sickle cell disease is a genetic condition which affects approximately 100,000 persons in the U.S., mostly African American¹. Persons with sickle cell disease can experience significant morbidity throughout life, as well as early mortality². The hallmark symptom of sickle cell disease is the vaso-occlusive crisis, which is an episodic event of severe pain which often requires hospitalization, typically to internal medicine services, and treatment with opioids.

Adults with sickle cell disease consistently report negative interpersonal healthcare experiences³⁻⁷. The interpersonal healthcare experiences of adults with sickle cell disease have been characterized as encompassing mistrust from clinicians, stigmatization, lack of control, and neglect⁸. That is, sickle cell patients report that the legitimacy of their pain is often doubted by healthcare professionals, that they are stigmatized as drug-seeking, that they are not typically included as partners in the medical relationship, and that their needs are often neglected while hospitalized⁸.

Despite the body of literature documenting the negative interpersonal healthcare experiences of adults with sickle cell disease, no studies have examined the trust *that persons with sickle cell disease have toward the medical profession* (as opposed to the trust that clinicians may have, or fail to have, in sickle cell patients as noted above). Trust is a central feature of the patient-physician relationship, and patient trust in physicians and the medical profession has consistently been found to be associated with the quality of the patient-physician relationship, satisfaction with care, continuity of care, willingness to seek care, willingness to follow physician's recommendations, adherence to therapy, and self-reported health status⁹⁻¹³. Trust in the medical profession may be particularly important for patients with sickle cell disease, who have been shown to underutilize recommended medical therapies¹⁴.

The aim of this study was to assess the level of trust toward the medical profession among adults with sickle cell disease, and to test the hypothesis that lower trust would be associated with poorer patient ratings of the quality of their previous communication from providers, which is one specific aspect of prior interpersonal healthcare experiences.

Received May 5, 2009

Revised November 4, 2009

Accepted December 30, 2009

Published online March 3, 2010

RESEARCH DESIGN AND METHODS

Study Design, Setting and Sample

We conducted a cross-sectional study of adults (age 18+) with sickle cell disease receiving care at an urban academic medical center from September 2006 to June 2007.

Data Collection

Eligible patients were recruited from the adult sickle cell and hematology outpatient clinics, the emergency department (ED), the inpatient units, or within 5 days after discharge from the hospital. Participating patients underwent a 15-minute interview by a trained study team member and received \$10 for interview completion. Health status information was abstracted from the patient's medical record. The academic medical center's institutional review board reviewed and approved the study procedures, and all participating patients gave informed consent.

MEASURES

Patient Trust

Patient trust toward the medical profession, the dependent variable, was assessed using the Wake Forest Trust in the Medical Profession scale¹², which operationalizes trust as the optimistic acceptance of a vulnerable situation in which one party believes that its interests will be cared for by another party¹⁵. Respondents expressed their level of agreement with the following statements: 1) Sometimes doctors care more about what is convenient for them than about their patient's medical needs (reverse coded); 2) Doctors are extremely thorough and careful; 3) You completely trust doctors' decisions about which treatments are best; 4) A doctor would never mislead you about anything; and 5) All in all, you trust doctors completely. Higher levels of trust on this measure are associated with greater trust in a specific physician, greater satisfaction with care, and following a doctor's recommendation, while lower levels of trust are associated with having had a prior dispute with a physician, having sought a second opinion, or having changed physicians¹². Scores on each of the items were summed, and then transformed onto a 0 to 100 scale. Higher scores indicated greater trust. This measure demonstrated good internal consistency in our sample with a Cronbach's alpha of 0.80.

Provider Communication

Patient ratings of provider communication, the independent variable, were measured using the Provider Communication subscale of the Consumer Assessment for Healthcare Plans and Systems survey¹⁶. Respondents were asked to rate the extent to which their healthcare providers in the prior year listened carefully, explained things clearly, showed respect for what the respondent had to say, and spent enough time with the respondent. By convention, scores on each of the provider communication items were summed, and then transformed onto a 0 to 100 scale. Higher scores indicate better ratings of provider communication¹⁷⁻¹⁹. This measure demonstrated excellent internal consistency in our sample with a Cronbach's alpha of 0.90.

Covariates

We assessed a number of patient demographic, clinical, and attitudinal characteristics as potential confounders. Patient age was assessed as a continuous variable. Categorical demographic variables assessed were patient sex, education (<high school, high school/GED, some college, college or beyond), annual household income (<\$10,000; \$10,000 to \$35,000; and \geq \$35,000+), and indicator variables for current employment (employed/unemployed), school status (in school/not in school), and receipt of disability (yes/no).

We assessed the following categorical clinical variables related to the patient's health status: the patient's sickle cell type (HbSS vs. other), indicator variables for non-sickle related comorbidities (diabetes, hypertension, HIV, hepatitis B, or hepatitis C), a categorical variable assessing the number (0, 1, 2, or 3+) of sickle-related comorbidities (acute chest syndrome, avascular necrosis, renal disease, pulmonary hypertension, or iron overload), and a categorical variable assessing the patient's self-report of their annual hospital utilization for treatment of vaso-occlusive crises (<1, 1-3, 3-10, 10+).

Two continuous patient attitudinal variables were measured. Dispositional optimism was assessed by the Life Orientation Test-Revised, which appraises the extent to which individuals have positive expectations for the future²⁰. Locus of Control was assessed using the Multidimensional Health Locus of Control subscales, which measure the extent to which individuals believe their health is determined by their own actions (internal locus of control), by chance (external locus of control: chance), or by health professionals (external locus of control: powerful others)²¹.

Finally, we assessed the patient interview setting (inpatient vs. outpatient) as a categorical covariate of interest to determine if differences in trust were associated with the interview site.

Statistical Methods

Bivariate associations among the variables were examined using Pearson correlations, chi-square tests, t-tests, and one-way analysis of variance as appropriate. Patient characteristics associated with provider communication ratings or trust at a p-value \leq 0.20 in bivariate analyses were retained for inclusion in subsequent regression models.

The independent association of provider communication ratings with trust was assessed using four multiple linear regression models. In model 1, we assessed the unadjusted association between provider communication and trust. To this model, we sequentially added the patient demographic variables (model 2), clinical variables (model 3), and the attitudinal variables (model 4). Regression models were restricted to the subset of patients with complete data on all variables of interest (n=82). Results for the regression of trust on provider communication ratings are presented both in terms of percentage change (in the text), and as beta coefficients (text and tables). We used two-sided p-values for all analyses, with a p-value \leq 0.05 as the threshold for statistical significance in the regression analyses. All statistical tests were performed using Stata 9.2 software²².

RESULTS

Ninety-five adult sickle cell disease patients were enrolled in the study out of the 96 that were approached. The characteristics of

Table 1. Patient Characteristics (N=95)

Demographic characteristics	
Age, mean(SD)	32.9(10.5)
Female, %	58.9
African American, %	100
Education, %	
Less than high school	11.6
High school	36.8
Some college	28.4
College & beyond	23.2
Annual household income, %	
<\$10,000	31.9
\$10,000 to \$35,000	31.9
\$35,000+	36.3
Unemployed, %	67.4
Currently in school, %	16.8
Currently on disability, %	60.0
Recruitment setting	
Inpatient, %	50.5
Clinical characteristics	
HbSS Disease, %	63.8
1 or more non-sickle comorbidities, %	31.6
Number of sickle comorbidities, %	
0	22.1
1	32.6
2	27.4
3+	17.9
Hospital utilization for painful crisis, %	
<1 per yr	22.8
1-3 per yr	30.4
3-10 per yr	28.3
10+ per year	18.5
Attitudinal characteristics	
Interpersonal trust, mean(SD)	53.0(21.4)
Rating of provider communication, mean(SD)	68.6(24.8)
Optimism, mean(SD)	21.5(4.3)
Internal locus of control, mean(SD)	26.3(5.8)
External locus of control: chance, mean(SD)	20.7(5.9)
External locus of control: powerful others, mean(SD)	24.4(5.7)

the study sample are described in Table 1. Trust scores were normally distributed with a mean (SD) of 53 (21.4). Provider communication ratings were left skewed with a mean (SD) of 68.6 (24.8).

Unadjusted associations among trust, provider communication ratings, and patient characteristics are shown in Tables 2 and 3. Better ratings of provider communication were associated with higher levels of trust toward the medical profession (Pearson’s $r=0.51$, $p<0.001$). Higher trust was associated with lower education, lower household income, not being in school, less frequent hospital utilization, higher internal locus of control, and higher external (powerful others)

locus of control. Better ratings of provider communication were associated with older patient age, lower household income, and less frequent hospital utilization. Reported levels of trust were not found to be significantly different between those patients interviewed as inpatients and those interviewed as outpatients (51.8 vs. 54.2, $p=0.59$).

The results of regression models examining the association of provider communication ratings with trust with and without adjustment for potentially confounding patient characteristics are located in Table 4. Model 1 displays a significant unadjusted positive association between provider communication ratings and trust ($\beta=0.42$, $p<0.001$). That is, patient trust increased by 0.42 points on average with each 1 point increase in provider communication rating. In terms of percentage change, this result meant that a 10% increase in provider communication ratings was associated with a 5.36% increase in trust scores (95% CI [3.32%, 7.39%]). While the strength of the relationship was attenuated slightly upon adjustment for covariates, better provider communication ratings continued to be associated with greater levels of trust after adjustment for each of the retained covariates at each sequential step of model building. In the final fully-adjusted model (Model 4; $\beta=0.30$, $p<0.001$) a 10% increase in provider communication ratings was associated with a 3.76% increase in trust scores (95% CI [1.76%, 5.76%]).

After adjustment for patient characteristics and provider communication ratings, we also found independent associations between lower trust and having some college (vs. less than high school) education ($\beta=-18.28$, $p=0.007$), having college or beyond (vs. less than high school) education ($\beta=-14.5$, $p=0.05$), being in (vs. out of) school ($\beta=-12.46$, $p=0.02$), having 3-10 (vs. <1) hospital visits each year ($\beta=-11.68$, $p=0.04$) and having 10+ (vs. <1) hospital visits each year ($\beta=-17.21$, $p=0.009$). Higher trust was associated with greater optimism ($\beta=1.14$, $p=0.009$).

DISCUSSION

Our study found that patient perceptions of the quality of their healthcare provider’s communication in the past year are significantly associated with current trust toward the medical profession among adults with sickle cell disease, independent of a number of potentially confounding patient demographic, clinical, and attitudinal characteristics. Our study suggests that among patients with sickle cell disease, trust is associated with the patient’s perceptions of the interpersonal quality of the medical interaction, independent of the individual patient’s

Table 2. Pearson Correlations among Trust, Provider Communication Ratings, and Continuous Patient Characteristics

	Trust	P Comm	Age	Optimism	LOC: Int	LOC: Ch	LOC: PO
Trust	—						
P Comm	0.51***	—					
Age ^a	0.17†	0.23*	—				
Optimism ^a	0.14†	-0.02	-0.05	—			
LOC: Int ^a	0.28**	0.10	0.18†	0.04	—		
LOC: Ch	0.01	-0.04	-0.05	-0.36**	0.16†	—	
LOC: PO ^a	0.27**	0.05	0.25†	-0.01	0.46**	0.35**	—

^aPotential confounder retained for multivariate analyses

† $p<0.20$, * $p<0.05$, ** $p<0.01$, *** $p<0.001$

Key:

P comm-provider communication; LOC: int-locus of control: internal; LOC: Ch-locus of control: chance; LOC: PO-locus of control: powerful others

Table 3. Bivariate Associations among Patient Characteristics, Provider Communication, & Trust

Patient characteristics	Provider communication ratings			Trust in the medical profession		
	(mean)	(sd)	95% CI	(mean)	(sd)	95%CI
Sex						
Female	68.8	24.2	(62.3, 75.4)	52.5	23.1	(46.2, 58.7)
Male	68.4	26.0	(59.7, 77.0)	53.8	18.9	(47.6, 60.0)
Education ^a						
Some HS	75.9	21.3	(61.6, 90.2)	65.9	21.3	(51.6, 80.2)
HS Grad or GED	69.0	25.3	(60.3, 77.7)	59.1	22.0	(51.6, 66.7)
Some College	65.0	25.5	(54.5, 75.5)	42.2	21.4	(33.4, 51.0)
College or beyond	68.6	25.6	(56.9, 80.2)	49.1	13.2	(43.2, 54.9)
Household income ^{a,b}						
<10 k	77.3	22.3	(68.7, 85.9)	61.8	21.7	(53.4, 70.2)
10 k to 35 k	65.4	26.1	(55.2, 75.5)	49.7	19.2	(42.4, 56.9)
35 k+	62.3	25.0	(53.3, 71.4)	49.7	21.9	(41.8, 57.6)
Employment status						
Unemployed	69.2	24.8	(62.9, 75.5)	53.2	22.8	(47.5, 58.9)
Employed	67.4	25.1	(57.9, 76.9)	52.6	18.4	(45.6, 59.6)
School status ^{a,b}						
Not currently in school	70.7	24.2	(65.2, 76.3)	55.6	21.2	(50.8, 60.5)
Currently in school	58.8	25.9	(44.9, 72.6)	40.3	18.2	(30.6, 50.0)
Disability status						
Not on disability	66.7	25.8	(57.9, 75.4)	52.3	17.7	(46.4, 58.2)
Currently on disability	69.9	24.3	(63.4, 76.4)	53.5	23.7	(47.1, 59.8)
Recruitment setting						
Inpatient	66.4	25.1	(58.9, 73.9)	51.8	23.2	(45.0, 58.6)
Outpatient	70.9	24.5	(63.6, 78.2)	54.2	19.6	(48.4, 60.1)
Sickle cell type ^b						
Other SCD	63.5	23.3	(55.4, 71.7)	53.5	22.0	(45.8, 61.2)
SS	71.3	25.5	(64.6, 78.1)	52.4	21.3	(46.8, 58.0)
# of non-sickle comorbidities						
0 non-sickle comorbidities	66.9	26.1	(60.3, 73.6)	53.1	22.0	(47.6, 58.6)
1 or more non-sickle comorbidities	72.2	21.9	(63.9, 80.3)	52.8	20.5	(45.2, 60.5)
# of sickle comorbidities						
0	70.0	26.5	(57.2, 82.8)	56.8	23.5	(45.7, 67.8)
1	65.5	24.5	(56.5, 74.5)	55.6	19.2	(48.6, 62.7)
2	70.0	25.9	(59.5, 80.5)	51.2	21.1	(42.6, 59.7)
3+	70.9	23.1	(58.6, 83.3)	46.3	23.3	(33.8, 58.7)
Hospital utilization ^{a,b}						
<1 per yr	80.0	24.0	(69.1, 90.9)	61.0	17.9	(52.8, 69.0)
1-3 per yr	72.5	23.9	(63.2, 81.8)	57.5	20.9	(49.4, 65.6)
3-10 per yr	63.7	19.8	(55.7, 71.6)	49.4	19.6	(41.5, 57.3)
10+ per year	55.9	28.1	(41.4, 70.3)	42.6	24.8	(29.9, 55.4)

^aAssociated with trust ($p < 0.20$)

^bAssociated with provider communication ratings ($p < 0.20$)

own attitudes or general outlook on life. This result is consistent with the findings of Jacobs et al. who found in their qualitative study of a group of African Americans that technical and interpersonal competence (including perceptions of the physician's caring, empathy, taking the time to listen, honesty, and keeping the patient's best interests at heart) were the primary factors which engendered trust in physicians²³. Furthermore, these findings are consistent with a large body of research in other patient populations which has shown that patient perceptions of the quality of their provider's communication are strong determinants of the trust that patients have in physicians^{9,10,15,24-26}.

As this is one of the first systematic examinations of trust among adults with sickle cell disease, a predominately African American patient population in the U.S., it is interesting to note that the mean trust score for our sample (53 on a 0 to 100 scale), is close to the mean trust score found using this same measure among a national sample of 502 predominately white adults with health insurance (mean trust=50 on a 0 to 100 scale)^{12,27}. This comparison may be compromised by the fact that members of

minority groups were not well-represented in the development and validation samples in which the trust instrument was initially tested. Although no systematic racial differences in the responses to the items were found in these developmental studies, the scale developers noted the importance of future studies which would validate their scales specifically in minority populations. Nevertheless, a comprehensive examination of the conceptual and empirical literature on trust gives us greater confidence in the construct validity of this trust scale in African American populations. This scale was designed to assess trust in medical professionals across five conceptual dimensions (fidelity, competence, honesty, privacy/confidentiality, and a "global" dimension). Qualitative studies of African American and other minority patients which have attempted to assess the determinants of physician trust among these groups have described dimensions which greatly overlap with the dimensions assessed by the trust measure used in our study^{23,24}. Therefore, although the instrument was not specifically developed for African American populations, it is reasonable to believe that it addresses many aspects of trust that are salient to African Americans.

Table 4. Multiple Linear Regression Models of Trust Toward the Medical Profession (n=82)

	Model 1	Model 2	Model 3	Model 4
	Unadjusted β	Adjusted β	Adjusted β	Fully Adjusted β
<i>Provider communication</i>	0.42*** (0.00)	0.40*** (0.00)	0.30*** (0.00)	0.30*** (0.00)
<i>Patient demographics</i>				
Patient age		-0.06 (0.76)	-0.16 (0.42)	-0.28 (0.15)
Education (reference: Less than high school)				
High school or GED		-1.73 (0.79)	-4.93 (0.45)	-1.90 (0.76)
Some college		-19.53** (0.01)	-21.89** (0.00)	-18.28** (0.01)
College or beyond		-13.85 (0.07)	-17.08* (0.03)	-14.50 (0.05)
Household income (reference: < \$10,000)				
\$10,000 to \$35,000		2.39 (0.66)	-3.70 (0.50)	-3.59 (0.48)
\$35,000+		3.38 (0.54)	-1.40 (0.79)	-0.96 (0.85)
In school: Yes		-7.10 (0.18)	-9.70 (0.06)	-12.46* (0.01)
<i>Clinical Characteristics</i>				
HbSS: Yes			-4.83 (0.24)	-5.47 (0.16)
Hospital utilization for VOC (reference: <1 per year)				
1 to 3 per year			1.13 (0.82)	-0.34 (0.94)
3 to 10 per year			-12.07* (0.03)	-11.68* (0.04)
10+ per year			-16.89* (0.01)	-17.21** (0.01)
<i>Attitudinal characteristics</i>				
Optimism				1.14** (0.01)
Locus of control: Internal				0.08 (0.82)
Locus of control: Powerful others				0.68 (0.07)
R ²	0.26	0.43	0.52	0.60
Adjusted R ²	0.25	0.36	0.43	0.51

p-values in parentheses (rounded to 2 decimal points)
p<0.05, ** p<0.01, *** p<0.001

It is interesting to note that in our sample of sickle cell disease patients, those with higher education and those currently in school had lower trust than patients with lower education or those not in school. Persons with sickle cell disease with higher educational attainment may have different expectations for the patient-physician relationship than persons with lower education. As the majority of sickle cell patients who seek hospital care are on medical assistance or other forms of public health insurance²⁸, medical professionals who care for this population

may assume lower educational levels among these patients. Perhaps these assumptions change provider behavior such that the expectations of those patients with higher education are not met, thus causing these individuals to develop lower trust toward the medical profession.

In our study, patients with more frequent hospital utilization for pain also had lower trust. Hospital utilization is a frequently used, though imperfect, measure of sickle cell disease severity. Among the general population, patients with lower trust have been shown to report worse self-reported health status. It is possible that patients with worse self-reported health perceive their interactions with healthcare providers as having “failed”, and thus these patients may develop lower trust in providers generally. Our finding, therefore, could reflect this general finding. It is also possible that patients with more frequent hospital utilization have less trust in primary care services, thus contributing to less frequent outpatient utilization and less stable disease control. While data on the association of outpatient healthcare utilization and inpatient sickle cell utilization is surprisingly limited, Epstein et al. recently found a marginally significant *positive association* between outpatient utilization and emergency department use among adults with sickle cell disease²⁹, and Carroll et al. recently found that adults with sickle cell disease categorized as “high utilizers” of inpatient care actually have more outpatient visits than those categorized as “low utilizers”³⁰. Another plausible explanation for our finding of more frequent hospital utilization being associated with lower trust is that medical professionals may have more negative attitudes towards those sickle cell patients with more frequent hospital utilization. One study which used hypothetical vignettes describing children with sickle cell disease found that nurses recommended lower pain medication doses for more frequently hospitalized children compared to less frequently hospitalized children even though the nurses did not rate the intensity of the children’s pain any differently³¹. Negative attitudes toward patients with more frequent hospital utilization could in turn negatively affect the quality of medical professionals’ interactions with these patients, thus affecting patient trust.

Finally, we found that sickle cell patient’s dispositional optimism, which appraises the extent to which individuals have positive expectations for the future, was independently related to trust. This finding is consistent with the conceptual and operational definition of trust utilized in the development of the measure used for this study¹⁵. Despite the relationship between optimism and trust observed in this study and hypothesized to exist conceptually, interpersonal healthcare experiences in the form of provider communication ratings maintained a strong and highly significant independent association with trust even after controlling for the association between optimism and trust.

Our study has several limitations. As a cross-sectional study, causal inferences regarding the relationships between previous provider communication and trust should be made with caution. The association we found between provider communication ratings and trust could be explained if persons with higher levels of trust toward medical professionals are predisposed to providing more positive ratings of provider communication than persons with lower levels of trust. Studies employing longitudinal designs are required in order to assess the potentially complex causal mechanism which relates patient trust to patient ratings of provider communication.

Also, because we sampled patients seeking healthcare at a single urban academic medical center, our results may not be generalizable to the larger sickle cell population. Patients who actively seek care from a medical center may have higher levels of trust than patients who prefer to manage their conditions at home or in other settings. Additionally, the patients in our study may have been sicker than those patients who do not, or only infrequently, seek care. Our study should be replicated in a community-based sample of sickle cell patients who receive their care in a variety of settings to determine the consistency of our findings.

Patient trust in physicians is necessary for the ideal patient-physician relationship, and is an essential indicator of the quality of medical care³². While provider communication is often thought of as a dimension of trust, it is important to be clear conceptually as to what exactly this means. As a dimension of trust, provider communication represents an aspect of providers which may engender, or fail to engender, trust in patients. Our study of adults with sickle cell disease found that patient ratings of the quality of their provider's communication are associated with patient trust, even after adjustment for potentially confounding patient characteristics. If our findings are shown to generalize to the sickle cell patient population at large, then sickle cell patient trust towards medical professionals might be considered for use as an indicator of healthcare quality for this population. Interventions aimed at improving the interpersonal skills of medical professionals who interact with sickle cell disease patients may be an important avenue towards improving clinical and patient perspective outcomes of care for all persons with the disease.

Acknowledgements: Dr. Haywood's effort was supported by a National Research Service Award Minority Predoctoral Fellowship from National Heart, Lung, and Blood Institute Grant #: 5F31HL082037-03. This study was conducted with grant support from the Johns Hopkins Blaustein Pain Research Fund. The funding agencies did not have a role in the design, conduct, or reporting of the study.

Conflicts of Interest: None disclose.

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