Original Contributions

Clinical Correlates of Initial Treatment Disengagement in First-Episode Psychosis

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Abstract

Aim: Early engagement in care is thought to reduce disabling social losses related to the duration of untreated psychosis (DUP), such as school dropout, homelessness, and incarceration, which contribute to chronic disability. Early-intervention services that promote recovery will not be effective if eligible persons drop out of treatment after an initial hospitalization for a psychotic disorder. We had the unique opportunity to examine the treatment disengagement rate of patients with early psychosis after an initial hospitalization. **Methods:** In a predominantly male, African-American, and socioeconomically disadvantaged group of 33 participants with first-episode psychosis assessed at initial hospitalization and six months after discharge, we compared clinical characteristics (medication adherence attitudes and behaviors, knowledge about schizophrenia, insight, symptom severity, and persistence of alcohol and drug use) among those who disengaged and people who engaged in care. **Results:** More than half (18, 54.5%) attended <3 outpatient appointments in the six months after hospital discharge and, of those, nearly all (15, 83.3%) attended no outpatient appointments. Disengaged people were much less adherent to medications in the past month and six months, and scored lower on medication adherence attitudes, knowledge about psychosis, and insight. They had greater positive symptom severity and a higher likelihood of continuing drug use. **Clinical Relevancy:** Initial treatment disengagement is very common among young people with first-episode psychosis and is associated with poorer clinical status. More research is needed on the causes of disengagement during this critical period and ways to improve initial treatment engagement among people with first-episode psychosis.

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Submitted: January 13, 2014; Revised: June 21, 2014; Accepted: August 5, 2014

Introduction

The "clinical staging" approach to schizophrenia and other psychotic disorders provides a logical framework in which different stages of the illness require different approaches and interventions (1). Interventions are needed to enhance initial treatment engagement during the critical period after a young person is hospitalized for a first episode of psychosis, when the goal of treatment is to resolve the first episode and return him or her to work or educational pursuits (2). Studies of adults with serious mental illnesses suggest that more than half (median of 58%) disengage from treatment after a hospitalization (3). Rates of disengagement

Clinical Implications

In the future, we need studies that elicit the factors that affect young people with early psychosis who do not view care as a pathway to a better future, never engage, "refuse to participate," and are "lost to follow-up" after their first contact with the mental health treatment system so that we can help to spare them the potentially "vicious cycle of negative experiences, coercion, disengagement, and relapse" described elsewhere (41). Interventions focused on clinicians and public education campaigns to encourage young people to increase help-seeking and treatment engagement have had little demonstrated effect on shortening duration of untreated psychosis (13). Successful linkage interventions connecting older adults to outpatient care include those that involve family, clear discharge plans, and beginning outpatient care before discharge (42-44), but it is not clear how these strategies will work with young people with early psychosis. Age-appropriate interventions that prevent dropout and encourage engagement may promote public safety and ease the burden experienced by first-episode patients, families, and communities by helping young people pursue a pathway *through* care.

in first-episode psychosis vary, with one recent review concluding that 30% of individuals disengage from services; however, the review only included articles about people who had been in services at least six months prior to disengaging (4). We know little about *initial* disengagement among first-episode psychosis patients, or disengagement that occurs within the first three follow-up appointments after an initial hospitalization for psychosis.

Treatment engagement is complex, and no "engagement best practices" exist (3, 5). Definitions of "engagement" range from a strong therapeutic alliance, to attending a specific number of follow-up appointments, to a person being able to identify a provider as his or her own (5-8). Ideally, engagement signals a high-quality relationship between a mental health professional, an autonomous person seeking treatment, and possibly a key supporter (e.g., a parent or other caregiver) (9-12). In this study, we used a standard measure of engagement in the current literature, which is attendance at three or more follow-up appointments after an initial hospitalization (3); those who attended less than three appointments in the six months after hospitalization were considered disengaged.

Among young people who drop out of treatment and so disengage, psychotic symptoms may continue on unchecked, and their duration of untreated psychosis (DUP) may therefore be prolonged (13). A longer DUP not only is associated with greater psychiatric symptoms, but also contributes to repeated incarcerations, hospitalizations, homelessness, interpersonal violence, and suicide, as well as poor recovery outcomes more generally (14-17). Preventing prolongation of DUP by better understanding early-treatment dropout will enable us to develop appropriate interventions to prevent disengagement and advance the field of early intervention.

In this study, we took advantage of observational data that allowed us to compare first-episode patients who engaged in treatment with those who did not (but who still attended a follow-up research assessment six months after their initial hospitalization). Despite a small sample size, we were able to estimate the prevalence of disengagement and demonstrate the extent to which those who disengaged differ from engaged patients in terms of key early-course clinical variables: medication adherence attitudes and behaviors, knowledge about schizophrenia, insight, symptom severity, and persistence of alcohol and drug use. Although our available sample size was small (though unique in that we had research data on individuals who had either engaged with *or disengaged from* care), observed differences are likely to represent the *minimal* differences that can be expected since those who disengage from both treatment *and* clinical research follow-ups are likely to be even more different from those who engage in treatment.

Methods

Setting and Sample

This study used longitudinal data from an observational study of predictors of DUP, the main study being cross-sectional (18-21). Participants were recruited from three hospital settings within the same geographic and economic area: an inpatient psychiatric unit in a large, urban, public-sector county hospital; a crisis stabilization unit in the same hospital; and, another crisis stabilization unit in an adjacent suburban county. In these settings, first-episode patients were in usual treatment (i.e., the public mental health system); no specialized early-psychosis services were available. Specifically, despite growing implementation of first-episode specialty programs, the hospitals from which participants were drawn had not yet developed these. The investigators were not aware of any available, local peer-led support groups such as Hearing Voices, Wellness Recovery Action Plan services, or other recovery-oriented services that have been promulgated in recent years. The study was an observational, rather than interventional, study; patients were given

standard follow-up appointments for a local community mental health clinic upon hospital discharge.

Participants were recruited if they were currently hospitalized for a first episode of a primary psychotic disorder (i.e., not due to an affective disorder or substance-induced disorder), between the ages of 18 and 40 years, and English speaking. Exclusion criteria included a known or suspected history of mental retardation, a score of ≤23 on the Mini-Mental State Examination (22, 23), a significant medical condition that could interfere with study participation, a lack of ability to give informed consent, a previous hospitalization for psychosis ≥3 months prior to the index admission, and previous outpatient treatment for psychosis lasting ≥3 months. Although we defined first-episode psychosis using the two latter criteria, a small proportion of participants had some sporadic mental healthcare contacts during adolescence or during the prodromal period. However, most participants were completely treatment-naive at the time of initial hospitalization.

Once recruited, consented, and enrolled, participants were administered a variety of measures and rating scales by masters- or doctoral-level research assessors. The assessors then attempted to stay in touch with participants through regularly scheduled phone calls, cards, and letters.

Thirty-three of the overall sample of 109 were assessed at a follow-up appointment six months post hospitalization. These 33 participants were compared to the other 76 first-episode patients from the overall sample that had completed a baseline research assessment but not an assessment at six months. The two groups did not differ with respect to any of the sociodemographic characteristics listed in Table 1 (all p>.35). The 33 participants re-assessed at six months also did not differ from the 76 first-episode patients only assessed at baseline in terms of baseline alcohol use, drug use, symptom severity, or insight (all p>.34).

Procedures and Materials

Participants' demographic characteristics were collected at the initial assessment, and participants were also classified as living above or below the federal poverty level based on the number of individuals living in the household, the household's annual income, and published federal guidelines for defining the poverty level in the year the data were collected. The psychotic disorders, mood disorders, and substance use disorders modules of the Structured Clinical Interview for DSM-IV Axis I Disorders (SCID) (24) were used to diagnose psychotic disorders and substance use disorders.

We used several structured questions to assess follow-up adherence and medication adherence. Participants were asked about: the number of outpatient appointments attended in the six months since hospital discharge, the average number of days per week adherent to medication

in the *past month*, and the average number of days per week adherent to medication in the *past six months*. Based on the first item, our *a priori* definition of treatment disengagement was attending <3 outpatient appointments in the six months since hospital discharge.

The *Medication Adherence Rating Scale* (MARS) was administered to determine participants' attitudes toward their medications. In this 10-item measure designed specifically for medication adherence in psychosis, participants are asked to answer "yes" or "no" to behaviors or attitudes they held in the past week (25). In this sample, Cronbach's internal consistency reliability coefficient was α=0.98.

The *Knowledge about Schizophrenia Test* (KAST) was previously designed for use in patients and family members in this setting. The KAST is a self-administered, 18-item, multiple-choice test, which measures participants' knowledge about schizophrenia (26). Cronbach's α in this sample was 0.69.

A modified version of the *Birchwood Insight Scale* (BIS) was given to participants to determine their level of insight and need for care. The scale consists of eight items to which the participant responds "agree," "disagree," or "unsure." The wording of BIS items was modified slightly to make it suitable for interviewer-, rather than self-administration. A higher total score indicates greater insight. The BIS has been shown to have an internal consistency of α=0.75 and a one-week test-retest reliability of r=0.90 (27). Our Cronbach's α was 0.82.

Current/past-month symptom severity was assessed with the *Positive and Negative Syndrome Scale* (PANSS) (28), rated by masters- or doctoral-level research staff using data gathered from a chart review and an in-depth, semi-structured interview. To assess inter-rater reliability of the PANSS subscale scores, intraclass correlation (ICC) coefficients were calculated using a two-way mixed (judges fixed) effects analysis of variance model in which three assessors were the fixed effect while twelve target ratings were the random effect (29). ICC coefficients for the three subscales (positive, negative, and general psychopathology) ranged from 0.69 to 0.92.

The *Alcohol Use Scale* (AUS) was rated to determine the level of alcohol misuse. It was specifically designed for persons with serious mental illnesses, consisting of a single item that asks the clinician or researcher to rate the use of alcohol over the past six months (30). Similarly, the *Drug Use Scale* (DUS) was rated to determine the level of drug misuse. The most commonly used substance besides alcohol was cannabis, which is consistent with the literature worldwide, although rates of use vary (31, 32). Inter-rater reliability of the AUS and DUS was previously documented, with kappa coefficients of 0.80 and 0.95, respectively (33).

For our analyses, we dichotomized the five categories into two, abstinent versus use (the latter including use without impairment, abuse, dependence, and dependence with institutionalization). That is, "alcohol use" and "drug use," which met the criteria of "use without impairment," is defined as an AUS or DUS score of 2, and all scores ≥2 were placed in the use category. Those who met the criteria of "abstinent" were given a score of 1.

Data Analysis

Distributional properties of all variables were examined. Participants were then dichotomized into those who had attended <3 outpatient appointments in the six months following hospital discharge (the "disengaged" participants), and those who had attended ≥3 outpatient visits (the "engaged" participants), this being a widely used measure of engagement (3). Groups were compared using χ^2 tests of association for categorical/binary variables, Student's t-tests for means of normally distributed variables, and Mann-Whitney U-tests for continuous variables with non-normal distributions. The significance level was set at p=0.05, and all tests were two-tailed. Effect sizes were computed as the difference between the two means divided by the pooled standard deviation (Cohen's d, with an effect size of around 0.2–0.3 being considered a "small" effect, around 0.5–0.6 being a "medium" effect, and 0.8 or greater being a "large" effect); the corresponding effect size for results of the Mann-Whitney U-test was calculated as r=z/√n.

Results

Sociodemographic Characteristics and Prevalence of Treatment Disengagement

Basic sociodemographic characteristics of the study sample (n=33) are shown in Table 1. The mean age at initial hospitalization was 22.9±4.5 years, and participants had completed 11.3±2.1 years of education on average. The majority of participants were male, African American, single and never married, living with family members, unemployed, and living below the federal poverty level. Six participants (18.2%) had a SCID-diagnosed alcohol use disorder (abuse or dependence), and 21 (63.6%) had a cannabis use disorder. SCID-based diagnoses of primary psychotic disorders included: schizophrenia, paranoid type (11, 33.3%); schizophreniform disorder (6, 18.2%); psychotic disorder not otherwise specified (5, 15.2%); schizophrenia, disorganized type (4, 12.1%); schizoaffective disorder, depressive type (3, 9.1%); schizoaffective disorder, bipolar type (2, 6.1%); and, brief psychotic disorder (2, 6.1%).

Table 1	Sociodemographic Characteristics of First-Episode Psychosis Patients (N=33)
Age at initial hospitalization, years	22.9±4.5
Educational attainment, years	11.3±2.1
Gender, male	27 (81.8%)
Race, African American	30 (90.9%)
Relationship status, single and never married	30 (90.9%)
Living with family members in the month prior to hospitalization	21 (63.6%)
Employment status, unemployed in the month prior to hospitalization	22 (66.7%)
Living below the federal poverty level (n=29)	19 (65.5%)
Presence of alcohol abuse or dependence	6 (18.2%)
Presence of cannabis abuse or dependence	21 (63.6%)

Among these 33 first-episode patients attending a research assessment at six months post hospitalization, 18 (54.5%) had attended <3 outpatient appointments in those six months, and 15 had engaged by attending ≥3 outpatient visits. Among the 18 who had disengaged, nearly all (15, or 83.3%) had attended no outpatient treatment at all in the six months post hospitalization.

Comparisons between First-Episode Patients Who Disengaged Versus Engaged in Treatment

Among the 10 sociodemographic variables listed in Table 1, the 18 disengaged first-episode patients differed from the 15 who had engaged only in terms of educational attainment (12.0±2.3 among the disengaged, compared to 10.5±1.7 among the engaged; t=2.07, df=31, p=0.047) and living below the federal poverty level (46.7% among the disengaged, compared to 85.7% among the engaged; χ^2=2.07, df=1, Fisher's exact p=0.05).

We then compared key clinical variables among those who disengaged and engaged in treatment. The disengaged differed significantly and meaningfully (see effect sizes in Table 2) from the engaged. Specifically, the disengaged reported much less adherence to medications in the past month and in the past six months, and had lower scores on medication adherence attitudes, knowledge about psychosis, and insight. The disengaged also had marginally significant greater severity of positive symptoms (though negative symptom severity and general psychopathology symptom severity did not differ; data not shown). The engaged were

Table 2 Comparisons of Clinical Characteristics among First-Episode Psychosis Patients (N=33) who Disengaged Versus Engaged in Treatment in the Six Months Following Initial Hospitalization

	Disengaged (n=18)	Engaged (n=15)	Test Statistic	p	Effect Size
Days per week, on average, adherent to medication, past month	0.6±1.8	4.6±3.2	z=3.46	.001	r=.60
Days per week, on average, adherent to medication, past six months	1.5±2.2	5.7±2.1	z=4.04	<.001	r=.70
Medication adherence attitudes (MARS)	4.5±1.5	5.9±1.7	t=2.15	.041	d=.87
Knowledge about psychosis (KAST)	8.5±3.2	12.0±2.9	t=3.17	.004	d=1.15
Insight (BIS)	5.4±3.4	7.9±2.4	t=2.39	.023	d=.85
Positive symptom severity (PANSS)	22.8±8.8	17.2±7.7	t=1.89	.069	d=.68

less likely to have drug use at six months (26.7%) than the disengaged (61.1%; χ^2=3.92, df=1, p=.05), as shown in Figure 1. Similarly, the engaged were less likely to have alcohol use at six months (46.7%) than the disengaged (72.2%), though this finding did not reach statistical significance. Of note, insight and positive symptom severity did not differ significantly at baseline (initial hospitalization): BIS scores of 5.4±2.7 among those who would later disengage and 6.4±4.1 among those who would engage (t=0.89, df=30, p=.381) and PANSS positive symptom severity scores of 23.9±4.8 among those who would later disengage and 24.9±4.3 among those who would engage (t=0.66, df=31, p=.516). The level of alcohol use and drug use also did not differ at baseline (drug use is shown in Figure 1).

Discussion

In this sample, disengagement was very common, and was prominently associated with medication adherence attitudes and behaviors, knowledge about schizophrenia, insight, positive symptom severity, and drug use. Regarding the latter, disengagement was associated with persistence in drug use, whereas engagement was associated with a marked decrease in drug use at six months. Importantly, such differences were not apparent at baseline, and the only demographic differences at baseline were somewhat counterintuitive (lower educational attainment and a lower likelihood of living in poverty among those who later engaged in care).

In this setting, there was very little continuity of care between inpatient and outpatient settings with regard to the treating clinicians. Outpatient clinics were not in the immediate vicinity of the hospital. Being referred to an unfamiliar doctor at a clinic that is unfamiliar to the patient clearly can disrupt the transition from inpatient to outpatient care. Patients were referred to routine adult care in community

mental health settings, which would have centered on medication management. No specialty substance abuse services were part of routine care, and access to individual psychotherapy and group therapy was limited.

Furthermore, many of the participants were struggling with fragmented families and disadvantaged communities. Although we did not measure family involvement in care, this obviously might also contribute to treatment engagement. As mentioned above, no peer-led groups or specialty programs such as substance use services were available, which could also account for poor treatment engagement in this sample. Disengagement in first-episode psychosis is a serious problem even in the context of specialty early-intervention services. One article investigating people who actively refused any contact with a treatment facility after an initial hospitalization for psychosis suggested an initial disengagement rate of 23.3% over 18 months (with the first rating of disengagement pertaining to 6 months post hospitalization) and involved people who were not completely lost to follow-up after their initial hospitalization (34). Another study found that during 12 months, about 34% of first-episode patients disengaged (35). Given the magnitude of the problem of disengagement, even in the context of early-intervention programs where such services are available (4), more research is needed on the causes of disengagement during this critical initial period. Additionally, testing the effectiveness of measures designed to improve treatment engagement among young people with early psychosis is crucial.

Given the high prevalence of treatment disengagement and the clear clinical consequences, strategies to improve outpatient treatment engagement are important for the otherwise "lost to follow-up" or disengaged group, which may accumulate greater illness burden and psychosocial impairment. There is a growing literature on pathways to care (to

| Figure 1 | Prevalence of Drug Use among First-Episode Psychosis Patients who Engaged with Care (Blue) Compared to those Who Disengaged from Care (Red) |
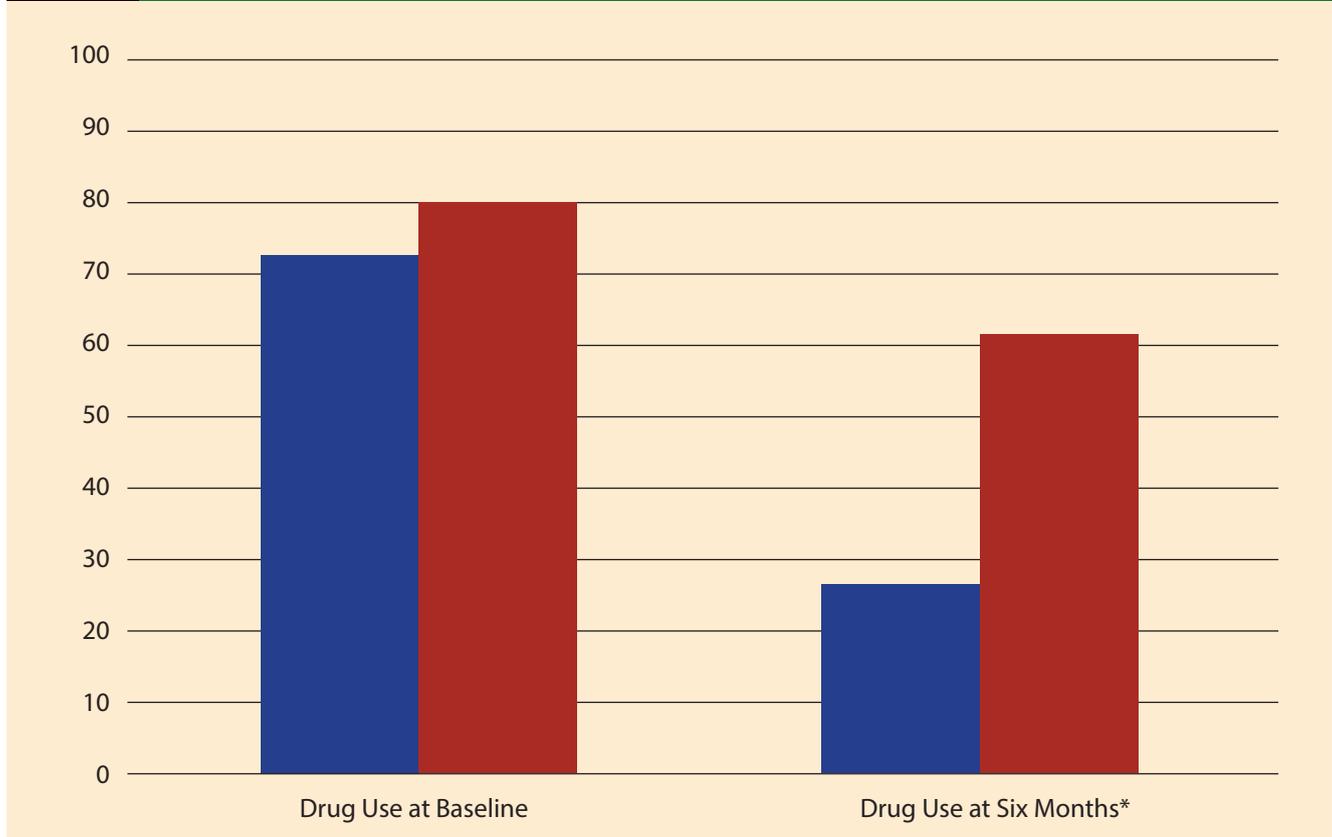
*Statistically significant difference at six months, p=0.05

the initial evaluation for psychosis) (36, 37), but there is virtually no research on "pathways through care," or decision making after the initial hospitalization that leads to consistent outpatient treatment engagement. While there are interventions that promote important clinical outcomes related to the findings of this study, such as shared decision-making for medication adherence (38) or targeted cognitive-based therapy for cannabis abuse (39), we still do not know how to get young people to use those services either initially (getting in the door) or in an ongoing, long-term way, which is important for the success of such interventions.

How do we develop interventions that help young people with early-course psychosis recover and work toward their own life and treatment goals? Ethnographic methods are appropriate for this line of inquiry because they generate hypotheses from person-centered data. At this stage, we cannot presume how first-episode patients decide to engage in initial treatment. An ethnographic approach may shift the inquiry around continuity of care beyond *predictors* of disengagement (e.g., time to first appointment [40]) and "pathways to care" (36) (e.g., contacts with emergency rooms, school counselors, or the police) to include the lived experiences, perspectives, and needs of young adults as they seek a "pathway through care"—out of the hospital and back to their homes and lives while pursuing recovery.

Several methodological limitations of this study are noteworthy. First, our sample size was very limited. Yet, to our knowledge, studies on first-episode patients who have disengaged from treatment are rare. Furthermore, the large effect sizes noted in our comparisons of clinical features indicate that such differences are detectable even in a small sample. As noted earlier, our findings likely underestimate the true effects (given that our "disengaged" participants were still engaged enough to attend a follow-up research appointment), tending, if anything, to bias our results toward the null. Second, the demographic characteristics of our study sample might limit generalizability to dissimilar samples. For example, the majority of participants were male, African American, single, living with family, unemployed, and impoverished; causes and consequences of treatment disengagement may be somewhat unique in a relatively homogeneous sample like ours. Third, the clinical characteristics of our sample and the health services setting (first hospitalization for initial evaluation, no specialized early-

intervention services) might also limit generalizability to dissimilar settings. Fourth, although we followed up with patients who went into psychiatric care and those who did not, we did not assess their full mental health service utilization. For example, it is possible, though rare based on our clinical experience with this population, that a small portion of patients might have used substance-abuse treatment services, which may have resulted in the reduction in drug use that we observed at six months. Finally, self-reports of medication adherence may be inaccurate and are always a potential limitation.

In the future, we need studies that elicit the factors that affect young people with early psychosis who do not view care as a pathway to a better future, never engage, "refuse to participate," and are "lost to follow-up" after their first contact with the mental health treatment system so that we can help to spare them the potentially "vicious cycle of negative experiences, coercion, disengagement, and relapse" described elsewhere (41). Interventions focused on clinicians and public education campaigns to encourage young people to increase help-seeking and treatment engagement have had little demonstrated effect on shortening DUP (13). Successful linkage interventions connecting older adults to outpatient care include those that involve family, clear discharge plans, and beginning outpatient care before discharge (42-44), but it is not clear how these strategies will work with young people with early psychosis. Age-appropriate interventions that prevent dropout and encourage engagement may promote public safety and ease the burden experienced by first-episode patients, families, and communities by helping young people pursue a pathway *through* care are greatly needed.

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