The Association Between Life Chaos, Health Care Use, and Health Status Among HIV-Infected Persons

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BACKGROUND: Whether having a stable and predictable lifestyle is associated with health care use and health status among HIV patients is unknown.

OBJECTIVE: To develop and test the reliability and validity of a measure of life chaos for adults with HIV and examine its association with health care use and health status.

DESIGN: Prospective cohort study.

PARTICIPANTS: Two hundred twenty HIV-infected persons recruited from those who tested positive in a mobile testing van and from HIV clinics serving low-income populations.

MEASUREMENTS: Participants completed a survey every 6 months, assessing their health care use, SF-12 mental and physical health status and life chaos.

RESULTS: Cronbach's alpha for the six-item measure of chaos was .67. Those without a spouse or partner and those with one or more unmet social service needs, such as housing or transportation, had higher chaos scores. Compared to those with less chaos, those with more chaos were less likely to have two or more outpatient visits (adjusted odds ratio [OR] 0.48, 95% confidence interval [CI]: 0.24–0.98), more likely to have two or more missed visits (adjusted OR 2.30, 95%CI: 1.20–4.41) in the 6 months before study enrollment and had lower mental health status at enrollment and at follow-up. Life chaos was not associated with emergency department visits or physical health status.

CONCLUSIONS: We created a new measure of life chaos, which was associated with outpatient visits and mental health status. Chaos may be an important barrier to regular medical care. Future studies need to test this measure in more diverse populations and those with other diseases.

KEY WORDS: HIV/AIDS; health services research; utilization; health status.
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INTRODUCTION

The ability to be organized and on time are likely to influence certain important health behaviors including navigating the medical system, keeping clinic appointments, and adhering to treatment recommendations. Stressors, such as poverty, drug and alcohol dependency, and homelessness, may act as direct barriers to care,[1–4] but they also might affect health care by contributing to life chaos and instability. Thus, some have hypothesized that these stressors are associated with worse health care and worse health outcomes because they induce chaos or interfere with a person's ability to be organized.[5]

The impact of life chaos on health and health care has not been well examined. Matheny and colleagues developed the Confusion, Hubbub and Order Scale (CHAOS) to assess a child's home life regarding the amount of commotion, ability to find things, feeling rushed, ability to relax, having a calm atmosphere at home, and having a regular routine.[6] This measure was designed to be answered by parents about their child and only relates to the home environment. Previous studies have not directly measured life chaos in adults or examined its relationship to barriers, competing needs, use of care, or health outcomes. Persons with a chronic illness may be most prone to disruptions in health care and health status associated with chaos.

In the present study, we surveyed a cohort of HIV-infected persons in Los Angeles at high-risk of receiving inadequate care. We sought to develop a global measure of life chaos for adults regarding general aspects of life, not necessarily limited to the home environment. We also sought to test our hypotheses that life chaos is a measurable construct that is more prevalent among persons with lower socioeconomic status, worse social support (e.g., lack of spouse or partner), and more stressors (e.g., alcohol and drug use, having children, and unmet needs) and is associated with lower use of HIV care and worse health status.

METHODS

Study Sample

The Health Resources and Services Administration sponsored the Special Project of National Significance (SPNS), a multisite longitudinal study examining outreach interventions to help HIV-infected persons receive regular medical care. For this analysis, we examined data from one of ten programs (Los Angeles, Calif), which provided enhanced case management

services to patients in more convenient locations (e.g., streets and shelters) rather than in traditional clinic settings.

We recruited HIV-positive clients of the Drew Mobile HIV Testing and Outreach Van, which provides testing and counseling services in lower income Los Angeles neighborhoods. We also recruited subjects from a Los Angeles County public hospital HIV clinic waiting room. Because we sought persons at high risk of dropping out of care, subjects recruited from the HIV clinic were eligible if they self-reported a need for case management services or reported at least one missed medical visits in the last 6 months. All subjects also had to be 18 years or older and able to complete an oral survey in English or Spanish.

Data Collection

Bilingual research staff conducted face-to-face interviews in the subjects' preferred language (Spanish or English) at baseline between May 2004 and May 2005 and 6 and 12 months after baseline. At baseline, 223 subjects completed the survey, with 78% (174/223) and 76% (169/223) completing the 6- and 12-month follow-up surveys, respectively. Seven subjects (3%) died during the observation period.

Sociodemographics. We collected demographic information including age, race/ethnicity, education level, annual household income, health insurance, marital and parental status, and history of homelessness. We also asked about illegal drug use (excluding marijuana) and heavy alcohol use (five or more drinks in 1 day) in the last 30 days. We assessed HIV exposure risk factors, which we categorized based on the following descending hierarchy: injection drug use, male–male sexual intercourse, unprotected heterosexual intercourse, no reported exposure risk.

Health Measures. At each interview, subjects reported their most recent cluster of differentiation 4 (CD4) count in the last 6 months (<50, 50–199, 200–499, 500, or more) and health status using the Medical Outcomes Study Short-Form-12. We computed physical and mental component summary scores (PCS-12 and MCS-12) using standardized weights based upon a mean of 50 and a standard deviation of 10 in the general U.S. population with higher scores indicating better health status.[7]

Unmet Needs. At each interview, we quantified the number of unmet needs by asking participants if they needed assistance with substance abuse treatment, housing, finances, employment, transportation, food, benefits, child care, legal issues, needle exchange, interpreter/translation, and immigration. For each needed service, we asked whether participants received those services. A needed service that was not received was categorized as an unmet need.

Health Care Use. At each interview, participants reported the number of primary HIV care physician visits, emergency department visits (excluding visits for an acute injury such as a broken bone), and missed visits to their primary HIV care provider during the previous 6 months.

Chaos. The Confusion, Hubbub, and Order Scale (CHAOS) is a 15-item instrument specifically designed to be administered to parents for assessing chaos in the child's home.[6] To our knowledge, no measures of life chaos exist for adults. We adapted several of concepts measured by the CHAOS scale for adults, including the amount of daily routine, ability to plan and anticipate the future, and being on time. We changed the text of the items so that they assessed the person's life in general as opposed to restricting the item to home life. In addition, we added items related to money, employment, housing, and keeping appointments. We developed a set of 30 items, which we cut to 12 after iterative one-on-one cognitive interviews with HIV-infected persons revealed that several items were confusing or irrelevant to their lives. Administered at each interview, the 12 items consisted of self-referent statements with a five-point response set ranging from "definitely true" to "definitely false."

Statistical Analysis

We performed multi-trait scaling analysis[8] of the baseline data to evaluate item convergence and discrimination of the chaos scale. Item-scale correlations were examined to deter-

Table 1. Baseline Characteristics of the Study Sample

Baseline characteristics	
Female (%)	20.3
Age (%)	
18–34	16.2
35–49	61.3
50+	22.5
Race/ethnicity (%)	
White	8.6
African American	45.5
Latino	40.1
Other	5.9
HIV exposure (%)	
Men sex with men	10.8
Injection drug use	9.9
Heterosexual contact	71.6
Other	7.7
Annual Income (SD)	7,781 (7,877)
Education level (%)	
Less than high school	32.0
High school degree	41.4
Some college or more	26.6
Ever been homeless (%)	73.0
Currently uninsured (%)	45.5
Latest CD4 count (%)	
0–199 cells/ml	21.2
200–349 cells/ml	23.0
350–499 cells/ml	17.6
500+ cells/ml	38.3
Drug use in last 30 days (%)	48.2
Heavy alcohol use in last 30 days (%)	20.7
Two or more HIV care outpatient visits in last 6 months (%)	82.5
Two or more missed HIV visits in last 6 months (%)	46.3
One or more ER visits in last 6 months (%)	31.5
# of unmet needs	
0	24.8
1	12.2
2	15.8
3	47.3
Baseline Summary SF12 physical health score (SD)	44.3 (11.3)
Baseline Summary SF12 mental health score (SD)	42.2 (11.9)

Table 2. Items in the Chaos Scale

Item	Item-score correlation
1. My life is organized	0.64
2. My life is unstable	0.71
3. My routine is the same from week to week	0.50
4. My daily activities from week to week are unpredictable	0.50
5. Keeping a schedule is difficult for me[a]	0.69
6. I do not like to make appointments too far in advance because I do not know what might come up	0.64

Response scale is 1) strongly agree, 2) agree, 3) unsure, 4) disagree, and 5) strongly disagree. Responses to items 2, 4, 5, and 6 are reversed so that a higher score indicates more chaos. Item-score correlation is the correlation between each item and the scale of the combined items excluding that item.
Cronbach's alpha=.67

mine if each item correlated more highly with its hypothesized scale (corrected for item overlap with the scale) than with other scales (health status, unmet need). We eliminated items with lower correlations with the hypothesized scale, resulting in a set of six chaos items (Table 2). We measured internal consistency reliability using Cronbach's coefficient alpha.

We used linear regression to examine the association of chaos with sociodemographic and health characteristics and logistic regression to examine the relationship between chaos and health care use. We examined the number of primary HIV care visits, dichotomized at two or more versus fewer than two visits every 6 months because current HIV care guidelines recommend CD4 count and viral load assessment every 3 months.[2,9,10] We examined the number of emergency department visits (any versus none) and missed primary HIV care visits (one versus none; two or more versus fewer than two) in the last 6 months.

We used linear regression to examine whether chaos is a predictor of physical and mental health status. We performed these analyses with chaos dichotomized at the median and also as a continuous scale. We also controlled for baseline health status in a sensitivity analysis.

We eliminated three (2.4%) observations with missing values for the chaos and outpatient visit use variables. We weighted all analyses of follow-up outcomes to adjust for study attrition. Two separate attrition weights, one for each follow-up, were created based on separate logistic regression models predicting study attrition for reasons other than death. Covariates for both attrition models were baseline sociodemographics, drug and heavy alcohol use in the last 30 days, and history of homelessness and chaos. Weighted and unweighted results were similar. We used bootstrapping to estimate 95% confidence intervals (CI) for adjusted physical and mental health status scores. We used Stata 8.0 (College Station, Tex) for all analyses. The Institutional Review Boards of all participating institutions approved the study protocol, and all study subjects provided written informed consent.

RESULTS

Study Sample Characteristics

Of the 220 subjects in our study, 45% were African American, 40% were Latino, and 20% were women (Table 1). About one-third were not high school educated, almost three-quarters had a history of being homeless, and 45% were uninsured.

Table 3. Unadjusted and Adjusted Association Between Baseline Characteristics and Chaos Score

Predictor (comparison group)	Unadjusted		Adjusted	
	β (95%CI)	*P* Value	β (95%CI)	*P* Value
Age 18–34 years	.08 (−.28 to .44)	.67	.17 (−.20 to .53)	.37
Female (male)	−.03 (−.36 to .30)	.88	−.12 (−.55 to .31)	.57
Race/ethnicity (white)				
Black	.21 (−.28 to .70)	.40	.27 (−.21 to .75)	.28
Latino	.01 (−.48 to .51)	.96	.19 (−.32 to .70)	.47
Other race/ethnicity	−.15 (−.86 to .56)	.67	.04 (−.65 to .74)	.90
Married or has a partner	−.37 (−.73 to .00)	.05	−.44 (−.80 to −.09)	.01
Primary child care giver	.15 (−.46 to .76)	.63	.27 (−.37 to .90)	.41
Annual income>$8,000	.23 (−.03 to .49)	.09	.11 (−.25 to .48)	.55
Education (<high school)				
High School graduate	−.18 (−.49 to .13)	.26	−.25 (−.58 to .08)	.13
Some college or more	−.22 (−.57 to .13)	.21	−.31 (−.67 to .04)	.09
Ever been homeless	.42 (.13 to .71)	.005	.28 (−.04 to .59)	.08
Uninsured	.05 (−.22 to .32)	.71	−.13 (−.51 to .26)	.52
Illicit drug use in last 30 days	.18 (−.09 to .44)	.19	.01 (−.27 to .29)	.95
Heavy alcohol use in last 30 days	.28 (−.05 to .60)	.09	.24 (−.08 to .57)	.14
CD4 count <200 (CD4≥200)	−.06 (−.41 to .30)	.75	−.14 (−.55 to .27)	.50
HIV exposure (heterosexual)				
Male homosexual intercourse	−.48 (−.90 to −.05)	.03	−.41 (−.86 to .04)	.08
Injection drug use	.24 (−.20 to .69)	.28	.17 (−.29 to .62)	.46
Other exposure	−.14 (−.64 to .36)	.59	−.10 (−.69 to .49)	.74
One or more unmet needs	.71 (.42 to 1.00)	<.001	.62 (.32 to .92)	<.001
History of incarceration	.36 (.08 to .63)	.01	.12 (−.18 to .42)	.42
Has a case manager	−.23 (−.49 to .04)	.09	−.19 (−.45 to .07)	.16

The chaos score is standardized so that a standard deviation equals 1, range 6–30. The adjusted model includes all variables listed.

Table 4. Association Between Chaos and Health Care Use at Baseline and Follow-up

	Unadjusted odds ratio	95%CI	*P* value	Adjusted[a] odds ratio	95%CI	*P* value
Two or more outpatient visits with HIV provider in last 6 months						
At baseline	0.44	(0.25 to 0.80)	.007	0.48	(0.24 to 0.98)	.04
At 6 month follow-up	0.76	(0.25 to 2.30)	.63	0.35	(0.07 to 1.68)	.19
At 12 month follow-up	0.41	(0.15 to 1.15)	.09	0.38	(0.09 to 1.62)	.19
Two or more missed outpatient visits in last 6 months						
At baseline	2.30	(1.33 to 3.98)	.003	2.30	(1.20 to 4.41)	.01
At 6 month follow-up	1.47	(0.70 to 3.09)	.31	1.16	(0.45 to 2.99)	.76
At 12 month follow-up	1.72	(0.79 to 3.75)	.17	2.50	(0.94 to 6.68)	.07
One or more emergency department visits in last 6 months						
At baseline	1.58	(0.90 to 2.80)	.11	1.33	(0.69 to 2.57)	.39
At 6 month follow-up	0.80	(0.38 to 1.69)	.55	0.75	(0.30 to 1.92)	.55
At 12 month follow-up	1.61	(0.65 to 3.99)	.30	1.28	(0.42 to 3.88)	.66

[a]*Adjusted for baseline age, sex, race/ethnicity, annual income, education, spouse/partner status, history of homelessness, lack of health insurance, drug use in last 30 days, heavy alcohol use in last 30 days, CD4 count, HIV exposure risk group, and one or more unmet needs.*

About half reported using drugs in the last 30 days and 75% had reported one or more unmet needs. Eighty-three percent reported having seen a physician for HIV care at least twice in the 6 months before study recruitment. Forty-six percent missed two or more visits, and one-third had visited the emergency department at least once in the last 6 months.

Chaos Scale

Table 2 shows the six items comprising the chaos scale. The Flesch–Kincaid reading level of the items was 4.3. Constructed so higher values mean more chaos, scores were normally distributed, with 1.8% and 2.7% of subjects with the lowest and highest possible score, respectively. Baseline scores ranged from 6 to 30. The mean was 17.7 (SD 5.5) and median was 18 (interquartile range of 13–21). The mean chaos score at 6 months was 16.0, a difference of 0.96 (95%CI: 0.18 to 1.73) from baseline among those with non-missing chaos scores at follow-up. At 12 months, the mean chaos score was 16.2, a difference of 0.79 (95%CI: −0.01 to 1.6). Item-scale correlations (corrected for item overlap) ranged from 0.26 to 0.53. None of the chaos items correlated higher with unmet needs, history of homelessness, or physical or mental health status than they did with the construct (chaos) we hypothesized they would represent. Thus, discriminant validity of the chaos items was supported. Cronbach's alpha, a measure of internal consistency reliability, for the six-item scale was .67.

We examined the relationship between patient characteristics and chaos (Table 3) using linear regression with chaos scores rescaled to a standard deviation of 1. In bivariate analysis, having a spouse or partner (β=−.37, P=.05) and having male homosexual intercourse (β=−.48, P=.03) was associated with less chaos. Having a history of homelessness (β=.42, P=.005), previous incarceration (β=.36, P=.01) and having one or more unmet needs (β=.71, P<.001) was associated with greater chaos. In multiple regression, only marital status and having one or more unmet needs remained significantly associated with chaos.

Health Care Use

Having more chaos was associated with a lower likelihood of having adequate primary HIV care at baseline (i.e., two or more outpatient HIV care visits per 6-month period; odds ratio [OR]= 0.44, P=.007) with similar results after adjusting for sociodemographic and health characteristics, health insurance, history of homelessness and incarceration, heavy alcohol and drug use in the last 30 days, having one or more unmet needs, and having a case manager (OR=0.48, P=.04) (Table 4). Those with more chaos were less likely to have adequate primary HIV care at follow-up, but these findings did not reach statistical significance.

In unadjusted and adjusted analyses, greater chaos was associated with a greater likelihood of having missed two or

Table 5. Unadjusted and Adjusted Physical and Mental Health Status by Level of Chaos

	Unadjusted health status			Adjusted health status[a]		
	Low chaos	High chaos	Difference in health status[b] (95%CI)	Low chaos	High chaos	Difference in health status[b] (95%CI)
SF12 summary physical health						
At baseline	45.5	42.7	2.8 (−0.3 to 5.9)	45.0	43.3	1.7 (−1.4 to 4.8)
At 6 month follow-up	46.2	43.3	3.0 (−0.2 to 6.1)	46.0	43.6	2.4 (−1.3 to 6.1)
At 12 month follow-up	45.0	42.7	2.3 (−1.1 to 5.8)	44.9	43.2	1.6 (−2.2 to 5.4)
SF12 summary mental health score						
At baseline	46.4	37.0	9.4 (6.5 to 12.3)	46.3	37.3	9.0 (5.8 to 12.2)
At 6 month follow-up	47.4	40.3	7.1 (3.7 to 10.4)	48.1	40.2	7.9 (4.0 to 11.8)
At 12 month follow-up	47.3	40.1	7.2 (3.6 to 10.8)	47.4	39.6	7.8 (3.5 to 12.0)

[a]*Adjusted for baseline age, sex, race/ethnicity, annual income, education, history of homelessness, lack of health insurance, drug use in last 30 days, heavy alcohol use in last 30 days, CD4 count, HIV exposure risk group, and one or more unmet needs.*
[b]*Difference in health status between those with low chaos and those with high chaos.*

more outpatient visits in the 6 months before the baseline survey (Table 4). In the adjusted analysis, the relative odds of missing two or more visits was 2.30 times greater for those with more chaos compared to those with less chaos (P=0.01). At 6- and 12-month follow-up, more chaos was associated with a greater odds of having two or more missed visits, but these results were not statistically significant. In a sensitivity analysis using a cutoff of one or more missed visits, chaos was not associated with missed visits at baseline or follow-up. The direction of the association between chaos and emergency department visits at baseline was consistent with our hypothesis (i.e., more chaos is associated with emergency department use), but these findings were not statistically significant.

Physical and Mental Health Status

At baseline and follow-up, unadjusted and adjusted physical health status did not vary by chaos level (Table 5). In contrast, the adjusted baseline mental health status was worse among those with more chaos than those with less chaos (SF-12 MCS= 37.3 vs 46.3, respectively; difference of 9.0, P<.001). At 6- and 12-month follow-up, differences in mental health status scores between those with more and less chaos remained. Results were similar when examining chaos as a continuous variable. We also examined the association between chaos and follow-up physical and mental health status, controlling for baseline physical and mental health status. In these sensitivity analyses, chaos was no longer associated with mental health status at follow-up because of collinearity between baseline and follow-up mental health status.

Study Follow-up

The relative OR was 0.46 (P=.05) for attrition at 6 months and 0.78 (P=.52) at 12 months for those with less chaos compared to those with more chaos. For all analyses looking at outcomes at follow-up, we used attrition weights to account for the differential rates of follow-up by level of chaos and also by other demographic variables. The results for all of the analyses were similar with and without the use of attrition weights.

DISCUSSION

Whereas some have suggested that life chaos may be an important determinant of behavior and health,[5] very little is known about it. Among children, chaos in the home has been measured using a 15-item scale and is associated with lower socioeconomic status, worse emotional adjustment, delayed cognitive development, and more behavioral problems.[6,11,12] Previous studies have not directly measured chaos in adults. However, some research has implied that chaos may influence the health and health care of adults, having looked at issues of overcrowding, noise, and other similar factors.[13,14] A qualitative study of HIV-infected adults found poverty is associated with life "instability" and a "sense of uncertainty."[5]

With the goal of measuring instability, organization, the ability to anticipate the future, and to plan ahead, we developed a six-item instrument, which demonstrated acceptable construct validity and internal consistency reliability in a sample of disadvantaged persons with HIV. To reduce the possibility of endogeneity, we excluded specific environmental and personal factors that might cause life chaos, such as noise, overcrowding, unemployment, divorce, mental disorders, or barriers to care. This brief measure of global life chaos does not attempt to distinguish between potential subtypes of chaos (e.g., home, work, or psychological). Nonetheless, the psychometric properties of our measure suggest that the scale items capture a measurable construct of global life chaos that is related to, but different from, the associated constructs of unmet needs, mental health status, and other potential stressors.

Consistent with our hypothesis that having better social support and fewer stressors would lead to less chaos, having a partner or spouse and having no unmet needs were associated with less chaos. Contrary to our hypothesis, chaos did not vary by race/ethnicity, income and education or stressors, such as alcohol and drug use, homelessness, and having children. One possible reason for this lack of variation may be that our sample was fairly homogeneous with respect to sociodemographic and other characteristics.

Regarding health care use, persons with greater chaos were more likely to miss two or more visits in the 6 months before the baseline survey. Chaos was not associated with outpatient care at 6- or 12-month follow-up, although the direction and magnitude of the associations at follow-up were the same as at baseline. Some endogeneity bias might partly explain the association between chaos and health care use at baseline. Specifically, some subjects' recent experience getting to their medical visits might have influenced their response to the chaos items asking about their ability to make appointments and keep a schedule.

Although chaos was unassociated with physical health status, chaos was strongly associated with worse mental health status. Given the nature of the study design and the fact that mental health status was unchanged over the study period, we cannot determine whether greater chaos leads to worse mental health status or whether worse mental health status leads to greater life chaos. Of course, the relationship between chaos and mental health status may be bidirectional. Future studies following cohorts over longer time periods and measuring chaos and mental health status at multiple time points might help tease out the direction of the relationship.

Our study lacks generalizability given our sampling methods targeting persons with HIV who receive inadequate care and should be tested in other populations. Items 3 and 4 of our scale attempt to measure slightly different components of chaos (stability vs predictability). But if these two items continue to perform as similarly in other populations, one of these items could be eliminated to make the instrument shorter. Perhaps, in other populations, including those that are more diverse and those with other diseases, chaos might be more strongly associated with health care use and health status, and we might see a stronger association between socioeconomic variables and chaos.

Whereas the follow-up rate in the study exceeded 75% at both follow-up surveys, our analysis of health care use and health status at follow-up might have been biased because persons with more chaos were more likely to have been nonresponders. We used attrition weights to account for this difference in follow-up rate, but these weights may not have fully accounted for the potential attrition bias.

The present study is the first that we are aware of to measure chaos in adults and to examine its association with

health care use and health status. Our newly developed chaos measure demonstrated acceptable construct validity and internal consistency reliability, and its relationship with demographic characteristics, health care use, and health status was consistent with many of our hypotheses. Life chaos may be another important barrier to getting adequate care and may be a target for future interventions. Potential interventions might use reminders or other strategies to help patients be more organized, teach patients certain coping strategies to better deal with stressors, and use behavioral interventions to increase daily routines. Researchers should also consider the impact of noise, overcrowding, and other environmental factors on chaos and whether these factors might be additional targets for interventions. Finally, future clinical studies might consider measuring and adjusting for chaos when looking at health care use as an outcome.

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