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Treatment Seeking and Unmet Need for Care Among Persons Reporting Psychosis-Like Experiences

Jordan E. DeVylder, M.S.,

School of Social Work, Columbia University, New York City

Hans Y. Oh, M.S.W.,

School of Social, Columbia University, New York City

Cheryl M. Corcoran, M.D., and

Department of Psychiatry, Columbia University, New York City, New York State Psychiatric Institute, New York City., jed2147@columbia.edu

Ellen P. Lukens, Ph.D., M.S.W.

School of Social Work, Columbia University, New York City

Abstract

Objective: Psychosis-like experiences may be clinically significant given their demonstrated associations with concurrent psychological distress and the later development of diagnosable psychotic disorders. Prior studies of treatment for psychosis-like experiences have yielded conflicting results. The aims of this study were to investigate help seeking and need for care among individuals with psychosis-like experiences in a large general population sample.

Methods: Data from the Collaborative Psychiatric Epidemiology Surveys (N=10,541) were used to examine help-seeking behaviors among survey respondents who reported psychosis-like symptoms over a 12-month period. Adjusted odds ratios were calculated for a variety of help-seeking variables, with control for demographic factors and co-occurring psychiatric conditions.

Results : Among the 10,541 respondents, 3.4% reported a psychosis-like experience in the past 12 months. Respondents who reported psychosis-like experiences were more than twice as likely as those who did not to seek treatment. Those who reported such experiences but who did not seek treatment were more likely to have felt the need for or to have been encouraged by others to seek treatment and less likely to have felt that they had no psychiatric problem. Associations with unmet need for care were largely attributable to co-occurring psychiatric disorders.

Conclusions: Respondents with psychosis-like experiences had elevated rates of help seeking, as well as significant unmet clinical need among those not in treatment.

The conceptualization of psychosis as an extended phenotype warrants closer examination of individuals who report psychosis-like experiences but whose symptoms do not cross the threshold for clinical diagnosis (1,2). Psychosis-like experiences, which are more common than diagnosable psychotic disorders, have a median prevalence rate of 5.3% and a median

disclosures

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one-year incidence rate of approximately 3.1% (3,4). Few studies have examined psychosis-like experiences with respect to need for care and help-seeking behaviors.

Given that the onset of a psychotic disorder is often preceded by attenuated psychotic symptoms (5), psychosis-like experiences may be clinically significant as precursors to diagnosable psychotic disorders (6–9). Psychosis-like experiences have also been associated with distress, depression, and poor functioning (10–12). One general population study found that 29% of those reporting psychotic experiences had a significant need for care on the basis of clinician judgment, symptom severity, or functional impairment (13). Despite these findings, psychosis-like experiences can also be short-lived or innocuous, often remitting within two years (8,14). Unnecessary treatment for psychosis-like experiences poses the risk of being ineffectual and needlessly anxiety provoking, although lack of needed treatment may be even more detrimental.

The two studies examining treatment-seeking behaviors of individuals with psychosis-like experiences have yielded mixed results. In the Adult Psychiatric Morbidity Survey (N=7,266), people with psychotic experiences were significantly more likely to see general practitioners for emotional problems (but not for general medical problems) and to be in counseling or therapy; the odds of seeing a general practitioner or of being in counseling or therapy increased as respondents experienced more subtypes of psychotic symptoms (15). This finding was robust when the analysis controlled for demographic and clinical correlates of help seeking, including neurotic and substance use disorders. Conversely, Kobayashi and colleagues (16) conducted a case-control study comparing help-seeking outpatients (N=750) to non-help-seeking college students (N=781) and found that psychosis-like experiences were not associated with help-seeking behaviors when the analysis controlled for depressive symptoms. Given that psychotic experiences are highly comorbid with depressive and anxiety disorders (17–19), these findings suggest that help-seeking behaviors among people with these experiences may be explained by co-occurring psychiatric disorders, although it is then unclear why the effect was not eliminated with the inclusion of neurotic and substance use disorders in the study by Murphy and colleagues (15).

In this study, we used data from the Collaborative Psychiatric Epidemiology Surveys (CPES) (20) to examine help seeking and need for care among individuals with and without psychosis-like experiences. Specifically, we hypothesized that those with psychosis-like experiences will be more likely to receive mental health services; will have greater unmet clinical need, as indicated by an increased likelihood to have felt the need for or to have been encouraged by others to seek treatment; and will offer reasons for not seeking care that vary from the reasons offered by those who have not experienced psychosis-like experiences. Further, we examined whether these associations would be attenuated when the analysis controlled for co-occurring psychiatric conditions.

Methods

Participants

The CPES consists of data from three household surveys conducted in the United States with similar methodologies and content: the National Comorbidity Survey Replication (21), a

nationally representative sample; the National Latino and Asian American Study (22), a national area probability sample with supplements for adults of Latino and Asian national origin; and the National Survey of American Life (23), a nationally representative sample of African Americans, with Afro-Caribbean and non-Hispanic white adults drawn from the same source population and of similar socioeconomic status. All surveys utilized multistage clustered sampling designs, with random selection of households and household members within sampled census blocks.

In each of the surveys, trained lay interviewers conducted computer-assisted face-to-face or telephone interviews with respondents, aged 18 and over. The total number of participants from the three surveys was 20,013. For the study reported here, participants were excluded who did not respond to the psychosis items (N=6,920) or who had a lifetime diagnosis of a psychotic disorder (N=144). Participants were also excluded if they were age 65 or older (N=2,408) in order to avoid common medical or aging-related causes of psychosis-like experiences and to be consistent with prior studies (3). Our final sample included 10,541 participants. Demographic variables (age, sex, race-ethnicity, years of education, and marital status) were self-reported by respondents.

Diagnostic assessment

Twelve-month diagnoses of *DSM-IV* axis I disorders were assessed with the World Health Organization Composite International Diagnostic Interview (WHO-CIDI), a widely used and reliable structured interview for diagnosis (24). Affective disorders included major depressive disorder, bipolar I and II disorder, and dysthymia, collapsed into a dichotomous “affective disorders” variable. Anxiety disorders included generalized anxiety disorder, agoraphobia with and without panic disorder, panic disorder, social phobia, and posttraumatic stress disorder, recoded into a single “anxiety disorders” variable. Substance use disorders included alcohol abuse or dependence and drug abuse or dependence, recoded into a dichotomous “substance use disorders” variable. Logistic regression models (described below) were retested in a sensitivity analysis with lifetime rather than 12-month diagnoses.

Psychosis-like experiences

Respondents were asked to report the lifetime presence of six specific psychosis-like experiences from the WHO-CIDI 3.0 psychosis screen, including visual hallucinations, hearing voices, experiencing mind control, experiencing the mind being taken over by strange forces, communication attempts from strange forces, and unjust plot to harm you that no one else believed. This screen has commonly been used to measure psychotic experiences and is validated as a significant predictor of hospital admissions and the development of threshold psychotic disorder (25). Responses were excluded if the experience took place in the context of falling asleep, dreaming, or substance use. Respondents with any lifetime experiences were then asked whether the psychotic experiences occurred in the past 12 months. Several other variables characterizing lifetime psychosis-like experiences were included, specifically age at initial psychotic symptoms, number of times the symptoms were experienced, and number of different symptoms experienced.

Help-seeking variables

Data on help-seeking behavior were coded as seven dichotomous variables derived from survey questions included within an extensive segment assessing service utilization. First, participants were asked whether they had seen a mental health professional in their lifetimes, with mental health professional broadly defined: psychiatrist, psychologist, clinical social worker, or other medical or counseling professional seen for mental health reasons. For each professional endorsed, respondents were asked follow-up questions regarding date of their most recent visit and the number of visits over the past year. Any visit in the past 12 months was coded as “yes” to having seen a professional in the past year. Two questions assessing unmet need for care were asked of those who had not sought treatment in the past 12 months (Did you feel the need for treatment in this time? Were you encouraged by someone else to seek treatment?), and a third question assessed the self-reported cause (What was the reason for not seeking treatment?). The three common reasons for not seeking treatment were coded into separate dichotomous variables (did not feel there was a problem, felt able to handle the problem, or felt professional treatment would not be helpful).

Analyses

Analyses were conducted with the complex-sample features of SPSS, version 20. Statistical estimates were weighted by using CPES sampling weights to account for nonresponse and unequal probabilities of selection, as well as stratification employed in the sampling design, to ensure that the sample was representative of the U.S. adult population (aged 18–64). Design-based analyses were used to estimate standard errors that accounted for the complex multistage clustered design of the CPES sample.

Univariate differences in demographic, clinical, and help-seeking variables between respondents with and without psychosis-like experiences were tested by using Wald chi square tests (two-tailed, $\alpha=.05$). All seven help-seeking outcome variables were further examined for associations with 12-month psychosis-like experiences by using blocked hierarchical multiple logistic regression. In the first block, demographic variables (age, sex, race-ethnicity, years of education, and marital status) were entered as covariates in all regression models. In the second block, three clinical variables indicating the presence or absence of affective, anxiety, or substance use disorders were added to the model. For all multiple logistic regression analyses, significance was tested using Wald chi square tests (two-tailed, Bonferroni-corrected for multiple comparisons, $\alpha=.007$). Therefore, confidence intervals excluding 1.0 may not indicate significance in all analyses because of statistical corrections for multiple comparisons.

Results

All respondents were aged 18 to 64. As shown in Table 1, more than half were female, and the sample was racially and ethnically diverse. Of the 10,541 respondents, 358 (3.4%) reported a psychosis-like experience in the past 12 months. Those with 12-month psychosis-like experiences were younger, less likely to be currently married, more likely to be African American or Afro-Caribbean, less likely to be Asian, and more likely to have met criteria for a *DSM-IV* disorder in the past 12 months (Table 1). The two most commonly reported

psychosis-like experiences were visual hallucinations (66.5% of respondents) and auditory hallucinations (49.8%); less commonly reported subtypes included communication attempts by strange forces (11.5%), unjust plots of harm (9.2%), mind control experiences (6.7%), and experiences of the mind being taken over by strange forces (3.5%). The mean \pm SD age at onset of psychotic experiences was 23.3 \pm 3.9 years, and most respondents (64.1%) experienced a single subtype during their lifetime.

Just over 30% of the 358 respondents with 12-month psychosis-like experiences had sought mental health treatment in the concurrent period. In univariate Wald chi square analyses, all treatment variables assessed were significantly different between the two groups (those with and without 12-month psychosis-like experiences), except for endorsing the statement that professionals would not be helpful (Table 2). Treatment variables were then examined by using hierarchical multiple logistic regression. The associations between psychosis-like experiences and both help-seeking variables remained significant when the analysis controlled for demographic factors in the first model (Table 3). The inclusion of affective, anxiety, and substance use disorders in the second model weakened these associations slightly, but psychosis-like experiences were still associated with more than twice the odds of seeking treatment both in the concurrent 12-month period and lifetime (Table 3). For the respondents with 12-month psychosis-like experiences who did not seek treatment, psychosis-like experiences were associated with being encouraged by others to seek treatment (but not with feeling a need for care) when the analysis controlled for demographic factors in model 1; however, when clinical diagnoses were added to model 2, the associations with both of the need-for-care variables were no longer significant (Table 4). Finally, in the multiple logistic regression models, psychosis-like experiences were not significantly associated with variables assessing reasons not to seek treatment (Table 5). In a sensitivity analysis adjusted for lifetime rather than 12-month diagnoses of affective, anxiety, and substance use disorders, these results were not significantly changed (data not shown).

Discussion

The intent of this study was to answer three questions: whether people with psychosis-like experiences in the general population are more likely than those without psychosis-like experiences to seek clinical care, whether they are more likely to have an unmet need for care, and whether they vary from the population in reasons for not seeking care. We confirmed that when analyses controlled for demographic variables and co-occurring psychiatric symptoms, respondents who reported psychosis-like experiences were more than twice as likely as those who did not to seek treatment, both over their lifetimes (OR=2.2) and over the 12-month period corresponding to symptom presentation (OR=2.3).

When the analysis controlled for demographic factors only, those with psychosis-like experiences who did not seek treatment were more likely than those who did not report psychosis-like experiences to have subjectively felt the need for care (OR=1.8; not significant after the conservative statistical correction) and were more likely to have been encouraged by others to seek treatment (OR=2.7), although this unmet need was largely explained by the presence of co-occurring affective, anxiety, and substance use disorders.

These respondents who did not seek treatment tended to avoid treatment because they believed that they could handle the symptoms on their own (OR=1.9) and because they were less likely than respondents without psychosis-like experiences to report feeling that they did not have a psychiatric problem (OR=.5); however, these associations were not significant with statistical adjustment for multiple comparisons. Each of these main findings will be discussed in turn.

Our findings are consistent with those of Murphy and colleagues (15), who found elevated rates of help seeking for psychosis-like experiences in the Adult Psychiatric Morbidity Survey, controlling for a similar set of demographic and clinical predictors. In contrast, our findings run contrary to those of Kobayashi and colleagues (16). They also found a univariate association between psychosis-like experiences and help seeking, but the effect was explained almost entirely by the presence of depressive symptoms, whereas we found that the inclusion of affective, anxiety, and substance use disorders in our model did not eliminate the association between psychosis-like experiences and help-seeking variables.

This difference may reflect methodological differences in the assessment of psychotic experiences (WHO-CIDI 3.0 psychosis screen versus the PRIME Screen-Revised) and depression (*DSM-IV* diagnoses versus symptom scores on the Zung Self-rating Depression Scale), the size of the sample (10,541 versus 1,531), or the source population (U.S. general population versus community mental health clinic patients, with a control group of college students, in Tokyo). Of note, both our analysis and that of Murphy and colleagues (15) controlled for co-occurring diagnoses, whereas Kobayashi and colleagues (16) controlled for depressive symptoms. It is possible that psychosis-like experiences are frequently accompanied by subthreshold depressive symptoms that compared with diagnosable major depression may better account for increased help seeking.

Respondents with psychosis-like experiences who did not seek help were more likely to have felt the need for mental health treatment or to have been encouraged by others to get treatment, even though they did not obtain services, indicating the clinical significance of psychosis-like experiences even among those who do not access services. This is consistent with prior studies demonstrating that psychosis-like experiences are associated with distress, depressive symptoms, and impaired functioning (10–12,14). However, these associations were not significant when clinical diagnoses were included in our models; all our models were associated with substantially increased odds of both feeling a need for treatment and being encouraged by others to seek treatment (OR range 2.2–4.2). This would suggest that psychosis-like experiences frequently occur in the context of diagnosable *DSM-IV* disorders and that these co-occurring psychiatric disorders explain much of the unmet need for care. However, such co-occurrence does not negate the clinical significance of psychosis-like experiences, because such experiences have been found to be associated with increased severity of the primary diagnosis (that is, earlier onset, poorer illness course, greater service utilization, and increased suicidality) when they occur in the context of affective and anxiety disorders (18,26,27).

With respect to the three reasons for avoiding treatment, respondents with psychosis-like experiences who did not seek services were most likely to endorse the belief that they could

handle the problem on their own, although they were less likely than those without psychosis-like experiences to feel that they had no psychiatric problem. Those with psychosis-like experiences, therefore, were less likely to deny having a psychiatric problem and were more likely to recognize that they were experiencing clinically significant symptoms even though they did not seek help. Neither of these associations remained significant when the analysis adjusted for demographic characteristics and co-occurring psychiatric disorders, although associations diminished only slightly and remained significant at the trend level ($p < .1$). Notably, 50.5% of non-help-seeking respondents with psychosis-like experiences felt that they had no psychiatric problem, possibly reflecting the low clinical significance and distress associated with minor psychotic symptoms (8,13,14) or the use of effective coping strategies. Alternatively, this may reflect a lack of insight or awareness of symptoms, given that people with schizophrenia and other psychotic disorders report that they delayed treatment because they felt that they had no mental health problems (28,29).

A limitation of this study is that assessment of psychosis-like experiences in the general population through lay interview may be subject to the overreporting of “normal” experiences. However, this would likely bias our findings toward being more conservative rather than toward type I error, and false-positive screens may nonetheless be clinically meaningful because they are likewise predictive of diagnosable psychosis (25). We also did not measure trait schizotypy, which was recently shown to be protective against psychosis-related distress (30). Finally, our analyses did not allow us determine whether treatment seeking and need for care were attributable to the psychosis-like experiences specifically, although we did control for competing explanations of co-occurring disorders. Future studies should examine whether treatment seeking and need for care are attributable to psychosis-like experiences directly or rather to co-occurring symptoms and whether treatment is effective in alleviating symptoms and associated distress both concurrently and over time.

Conclusions

We found that individuals who reported psychosis-like experiences were more than twice as likely as individuals without psychosis-like experiences to seek treatment, even when the analysis controlled for a broad array of possible confounding factors, which supports the general clinical relevance of these symptoms. This study was motivated by two specific reasons for why psychosis-like experiences may be clinically significant: they may signify a risk of developing a diagnosable psychotic disorder and they may be distressing. Among people who may later develop a psychotic disorder, early treatment for psychosis-like experiences can reduce the duration of untreated psychosis and thereby contribute to a better clinical outcome (31) and may even prevent the onset of the diagnosable disorder (32). For those who may not develop a psychotic disorder, treatment may nonetheless alleviate some of the distress associated with psychosis-like experiences (10–14) and other co-occurring psychiatric conditions (17–19).

Given that respondents with psychosis-like experiences who did not seek help in the past year were approximately twice as likely to have been encouraged by others to seek

treatment, compared with those without psychosis-like experiences who likewise did not seek help, it appears that there is a substantial unmet need for clinical services among this subgroup. In addition, those who reported psychosis-like experiences were approximately twice as likely as those who did not to endorse being able to handle the condition themselves, which calls for outreach efforts that include psychoeducation, motivational interviewing, and related practices that promote mental health literacy (33,34). Alternatively, this response may indicate that these individuals were able to control and cope with their psychosis-like experiences, which may be further supported through cognitive-behavioral therapy (35). The findings may also have implications for youths attending clinical high-risk programs, where recruitment may be bolstered by appealing to family members, educators, and other community figures or by screening for psychosis-like experiences among youths who have diagnoses of affective, anxiety, or substance use disorders.

These findings underline the importance of further documenting the impact of psychosis-like experiences on help seeking and long-term care and outcome. Raising awareness of psychosis-like experiences among primary and behavioral health care providers and the general population is critical if we are to promote prevention, increased access to care, and more thorough assessment of the impact of intervention on this potentially vulnerable population.

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Demographic characteristics and diagnoses of 10,541 general population survey respondents, by whether they reported psychosis-like experiences^a

Table 1

Characteristic	Total sample		Psychosis-like experiences				Wald ^b	p
	%	SE	Yes (N=358)	%	SE	No (N=10,183)		
Age								
18–29	30.0	.9	36.4	3.1	29.8	.9	4.3	.037
30–44	37.0	.6	40.6	3.3	36.9	.6	1.3	.250
45–65	33.0	.9	23.1	3.3	33.3	.9	6.8	.009
Years of school completed								
<12	21.3	.9	25.1	3.2	21.1	.9	1.5	.227
12	30.3	1.0	30.0	3.5	30.3	1.0	.0	.942
13–15	25.4	.7	28.8	3.2	26.3	.7	.6	.440
>16	22.1	1.0	16.1	3.1	22.3	1.1	3.1	.079
Female	52.5	.5	55.8	3.4	52.4	.5	1.0	.315
Race								
African American	21.4	1.2	28.6	3.2	21.2	1.2	6.4	.011
Afro-Caribbean	1.6	.1	2.7	.6	1.6	.1	5.3	.021
Asian	10.4	.8	6.4	1.5	10.5	.8	4.6	.033
Caucasian	41.0	2.3	35.2	4.3	41.2	2.4	1.4	.232
Hispanic	24.3	1.6	26.9	3.8	24.2	1.6	.6	.453
Other	1.4	.2	.3	.3	1.4	.2	3.5	.061
Marital status								
Single	26.6	.7	38.0	3.9	26.2	.8	9.5	.002
Married	57.5	.7	40.3	3.5	58.0	.7	23.6	<.001
Previously married	15.9	.6	21.6	2.7	15.7	.6	4.9	.026
Diagnosis								
Affective disorder	10.6	.5	19.1	2.7	10.4	.6	12.8	<.001
Anxiety disorder	14.7	.6	26.4	3.7	14.3	.6	14.2	<.001
Substance use disorder	4.3	.4	8.3	2.5	4.2	.4	5.2	.023
Any disorder	22.6	.8	38.3	3.8	22.1	.8	19.3	<.001

Weighted percentages and standard errors are adjusted for complex survey design to ensure that the sample was representative of the U.S. adult population (aged 18–64).

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Help seeking and need for care among 10,541 general population survey respondents, by whether they reported psychosis-like experiences^a

Table 2

Variable	N of respondents	Total sample		Psychosis-like experiences				Wald ^b	p
		%	SE	Yes (N=358)	%	SE	No (N=10,183)		
Help seeking									
Seen mental health professional	10,541	39.9	1.0	58.7	3.5	39.3	1.0	26.5	<.001
Lifetime									
Past 12 months	10,541	14.4	.7	30.4	3.4	14.0	.7	29.6	<.001
Need for care among non-help-seeking									
Felt need for treatment	6,210	11.3	.6	18.3	3.4	11.1	.6	5.6	.018
Encouraged to seek treatment	6,210	7.1	.5	16.4	4.4	6.8	.5	12.4	<.001
Reasons for not seeking treatment									
Did not have a problem	5,669	63.8	1.1	50.5	5.9	64.1	1.1	6.2	.013
Could handle the problem	5,669	28.0	1.0	40.0	5.8	27.7	1.0	5.4	.020
Professional treatment would not be helpful	5,669	4.4	.4	6.9	1.8	4.3	.4	2.5	.114

^aWeighted percentages and standard errors are adjusted for complex survey design to ensure that the sample was representative of the U.S. adult population (aged 18–64).

^bdf=1

Logistic regression models of predictors of help seeking among 10,541 general population survey respondents^a

Table 3

Variable	Lifetime treatment				12-month treatment			
	Model 1		Model 2		Model 1		Model 2	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Psychosis-like experiences	2.6	2.0–3.4	2.2	1.6–3.0	2.7	1.8–3.9	2.3	1.4–3.7
Current diagnosis								
Affective disorder			3.9	3.2–4.9			4.5	3.4–5.9
Anxiety disorder			2.9	2.4–3.7			2.1	1.7–2.7
Substance use disorder			2.9	1.8–4.7			2.7	1.5–4.6

^aOdds ratios were adjusted for age, sex, race-ethnicity, education, and marital status. All variables in all models were significant predictors (Wald χ^2 , Bonferroni correction, $p < .007$).

Logistic regression models of predictors of need for care among 6,210 respondents who did not seek care^a

Table 4

Variable	Felt need for care				Encouraged by others			
	Model 1		Model 2		Model 1		Model 2	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Psychosis-like experiences	1.8	1.1–2.8	1.3	.6–2.6	2.7	1.4–5.0	2.0	1.1–3.8
Diagnosis								
Affective disorder			3.6	2.5–5.0			2.2	1.5–3.4
Anxiety disorder			3.4	2.3–5.1			2.6	1.7–4.1
Substance use disorder			2.6	1.3–5.0			4.2	2.3–7.6

^aOdds ratios were adjusted for age, sex, race-ethnicity, education, and marital status. Reporting psychosis-like experiences was a significant predictor only in model 1 for encouraged by others; all other variables in all models were significant predictors (Wald χ^2 , Bonferroni correction, $p < .007$).

Logistic regression models of predictors of reasons for not seeking treatment among 5,669 respondents who did not seek care and provided an explanation^a

Table 5

Variable	No problem			Could handle problem			Professional couldn't help					
	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2				
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI				
Psychosis-like experiences	.5	.3-.9	.6	.3-1.1	1.9	1.1-3.1	1.7	.9-3.0	1.6	.8-2.9	1.1	.5-2.3
Diagnosis												
Affective disorder		.3	.2-.4		.3	.2-.4		2.5	1.8-3.5		2.5	1.5-4.3
Anxiety disorder		.4	.3-.5		.4	.3-.5		2.0	1.6-2.6		2.4	1.5-4.0
Substance use disorder		.7	.4-1.2		.7	.4-1.2		1.1	.6-2.0		2.0	1.0-4.1

^aOdds ratios were adjusted for age, sex, race-ethnicity, education, and marital status. Reporting psychosis-like experiences was not a significant predictor in any model. Having an affective or anxiety disorder was a significant predictor in all models that included these variables (Wald χ^2 , Bonferroni correction, $p < .007$).