DOES THE INCREASED RATE OF SCHIZOPHRENIA DIAGNOSIS IN AFRICAN-CARIBBEAN MEN IN THE UK SHOWN BY THE AESOP STUDY REFLECT CULTURAL BIAS IN HEALTHCARE?

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SUMMARY

Introduction: The UK-based AESOP study conducted over a two-year period in three UK sites simultaneously (London, Nottingham, and Bristol), is the largest study to date to conduct a first contact case-control study of psychosis. The study found that rates of schizophrenia were markedly elevated in both African-Caribbean and Black African people, in both sexes and across all age groups.

Subjects and methods: English language literature published up to 2016 was searched. The initial search included: PubMed, The Cochrane Library, and Web of Science. A second search was conducted using Medical Subject Headings (MeSH) and keywords. Studies selected for retrieval were assessed by two independent reviewers.

Results: The search yielded eight results, all of which supported the conclusion of an increased incidence of schizophrenia in Black African and Black Caribbean population in the AESOP study.

Conclusion: England is a multicultural landscape; multiplicity of cultures makes diagnosis difficult. The lessons we must learn from the AESOP study is the need for transcultural training and the removal of blinding to ethnicity when a large epidemiological study is conducted – psychiatrists need to be cognisant of cultures and aware of the context of symptoms.

Key words: AESOP – African Caribbean – Black African – schizophrenia – diagnostic methods

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INTRODUCTION

The UK-based AESOP study(Kirkbride et al. 2006; Morgan et al. 2006) conducted over a two-year period in three UK sites simultaneously (London, Nottingham, and Bristol), is the largest study to date to conduct a first contact case-control study of psychosis. The primary aim was to test hypotheses concerning social and biological factors which might explain the increased incidence of schizophrenia in the African-Caribbean population in the UK; with a secondary aim of determining the causes of the high incidence in this population, in the hopes of shedding light on the aetiology of schizophrenia in general. The study found that rates of schizophrenia were markedly elevated in both African-Caribbeans and Black Africans, in both sexes and across all age groups.

The results of these studies and their interpretation has been widely debated.

Some believe that the evidence from AESOP suggests that these high rates of distress in African-Caribbean men are real, and are a consequence of greater exposure to social disadvantages in this population (Cooper et al. 2008). These disadvantages — include exposure to discrimination, and abnormal family patterns, especially early separation of children from their parents, particularly fathers. Others contest that the high incidence of schizophrenia among African-Caribbean men in the UK is due to the culturally inappropriate ways of assessing people for mental illness coupled with institutional racism within mental health services and

society at large. The rates of schizophrenia reported in the Caribbean are not as high as those for the African-Caribbean population in the UK. However, nor are they as low as for the White British population in the UK (Hickling & Rodgersjohnson 1995). Critics assert that the approach of AESOP was flawed; using a method criticised as culturally insensitive by refusing to account for how populations in non-western cultures viewed health and illness.

SUBJECTS AND METHODS

English language literature published up to 2016 was searched.

Search

A systematic search was conducted to identify all relevant peer-reviewed and literature exploring schizophrenia diagnosis and incidence in African Caribbean men in the AESOP study. The search strategy included an electronic database search of PubMed, The Cochrane Library, and Web of Science using combination of MESH terms, and key words. Reference lists of the included studies were searched manually. A literature search was also conducted by examining the first 50 citations in a Google search.

PubMed: AESOP[All Fields] AND ("african continental ancestry group"[MeSH Terms] OR ("african"[All Fields] AND "continental"[All Fields] AND "ancestry"[All Fields] AND "group"[All Fields]) OR "african continental ancestry group"[All Fields] OR

"african"[All Fields]) AND ("west indies"[MeSH Terms] OR ("west"[All Fields] AND "indies"[All Fields]) OR "west indies"[All Fields] OR "caribbean"[All Fields] OR "caribbean"[MeSH Terms] OR ("caribbean"[All Fields] AND "region"[All Fields]) OR "caribbean region"[All Fields]) AND ("schizophrenia"[MeSH Terms] OR "schizophrenia"[All Fields]) – 7 results, 1 irrelevant.

- The Cochrane Library: AESOP AND schizophrenia 2 results, 2 irrelevant;
- Web of Science: AESOP [Topic] AND African Caribbean[Topic] AND schizophrenia[Topic] - 15 results, 7 irrelevant, 6 duplicate;
- Secondary source: Google "AESOP" AND "African Caribbean" AND "schizophrenia" AND "diagnosis"

RESULTS

Table 1 displays the characteristics of the 8 included articles.

DISCUSSION

The search yielded eight results, all of which supported the conclusion of an increased incidence of schizophrenia in Black African and Black Caribbean population in the AESOP study, despite work done by Hickling and Rodgersjohnson (Hickling & Rodgersjohnson 1995) that show the rates of schizophrenia reported in the Caribbean are not as high as those for the African-Caribbean population in the UK. However, nor are they as low as for the White British population in the UK. Various theories were suggested to account for this difference, however, this conclusion may be exaggerated due to flaws in the interview and diagnostic process.

One study (Morgan et al. 2009) explores abnormal family patterns, especially early separation of (black) children from their parents, particularly fathers, and their role in schizophrenia. However, the researchers seem to have extrapolated from association to cause in a complex situation. There may also have been bias in their sample as the control included many people who were more socially isolated and likely to endorse psychotic experiences. The screening for symptoms was done via the Psychosis Screening Questionnaire (PSQ) used has not been assessed for cross cultural validity so caution must be taken when interpreting results. These results beg the question: is using social issues to explain differences wise?

Two studies (Cooper et al. 2008, Reininghaus et al. 2010) show a correlation between perceived discrimination and psychosis. It is a logical step to understand that perceiving disadvantage would give rise to paranoid thoughts. The converse, that a paranoid view of the world may increase the perception of persecutory experiences, would also be a reasonable assumption. It

is clear that incidents of discrimination occur, and in any given society there will be groups who experience them more often than others, and ethnic groups for whom the experience is qualitatively different. Where individuals appraise such incidents as personally directed, they may regard them as persecutory, and persecutory patterns of thought may be initiated.

Dean et al. (2007), found a link between aggression in schizophrenia and Black males. However, this does not demonstrate a causal relationship. It is possible that the perceived aggression may lead to a misdiagnosis of psychosis. Indeed, Black males were more likely to access health services through police arrest and compulsory admission than White males (Morgan et al. 2005a, 2005b). A study found that rates of criminal conviction was found to be increased among black men with schizophrenia but not among other ethnic groups (Wessely 1998). It is also possible that some of the apparent aggression observed at first contact in this group is a function of negative interactions and possible conflict with mental health and criminal justice services.

Religious delusions feature heavily in the psychoses of Black population in relation to the White population. Studies prior to AESOP demonstrated increased rates of schizophrenia in patients from the Caribbean and West Africa; these patients included a high proportion of those with paranoid and religious phenomenology, and those with frequent changes of diagnosis (Littlewood & Lipsedge 1981). A later paper (Siddle et al. 2002), suggested that this increased rate was due to bias and errors in diagnosis. Littlewood and Lipsedge did not have a clear set of criteria for establishing religious delusions, so may have categorised inappropriately a number of people with religious beliefs who were not deluded. A proportion of these patients perhaps expressing some of the normal religious beliefs of their own culture would have been wrongly categorised as deluded. The interviewers were not blind to ethnicity (Siddle et al. 2002)so were able to categorise those from an Afro-Caribbean background as not meeting the criteria for religious delusions because their beliefs were culturally acceptable. This is an excellent example of how cultural differences play an integral role in interpreting psychosis symptomatology.

Social withdrawal was used as a primary diagnostic symptom for schizophrenia. This is a key stress suffered by immigrants. Previous studies (Cantor-Graae & Selten 2005, Pinto 1970) have shown the increased incidence of schizophrenia amongst the migrant population. This may be due to a combination of reduced social status, poor housing and increased social isolation. Second generation immigrants (born in the UK to parents of immigrant status) may experience stress and anxiety due to an effort to reconcile their two cultures (Dealberto 2007). Yet second generation immigrants were not taken into account in the AESOP study and may be another confounding variable.

Table 1. Results	of literature	search. IRR -	- incidence rate	ratio
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Citation	Study Group	Key results and Interpretation	Comments	
	AESOP	■ The incidence of all psychoses to be significantly higher in African-Caribbean and Black African populations across all three centres compared with the baseline White British population. These differences were most marked for narrowly defined schizophrenia (F20) and manic psychosis (F30-31).	 Diagnoses were made by consensus, blind to ethnicity on the basis of all available information, including data from SCAN interviews. 	
	■ The incidence rates for schizophrenia in the African-Caribbean and Black African populations (71 per 100,000 person years, and 40 per 100,000 person years, respectively) are among the highest ever reported.			
	■ The incidence rates for all psychoses were also raised for all other ethnic groups (other White, Asian, mixed, other) compared with the White British populations, albeit much more modestly.			
	■ Concluded that there marked excess of psychotic illness in African-Caribbean and Black African populations in the UK.			
Kirkbride et al. 2006		■ Adjusted IRRs for the BME group were significantly elevated for schizophrenia (IRR, 3.6 [95% CI, 2.7-4.9]).	■ Inspection of census data, stratified analyses, and	
	■ For all psychoses, the rate in Southeast London remained significantly higher than in either Nottingham (1/IRR, 1.3 [95% CI, 1.1-1.7]) or Bristol (1/IRR, 1.4 [95% CI, 1.1-2.0]), having adjusted for age, sex, and ethnicity.	modelling interaction terms involving the BME group and age indicated no evidence of modification of the study center effect by age or generation; this		
	■ 3-fold increased incidence of psychoses in the BME group compared with the white British group	excluded overrepresentation of second or third generation		
	 A tendency to preferentially classify symptoms as schizophrenia in BME groups cannot have led to these findings 	migrants in London explaining the excess.		
Fearon et al. 2006 AESOP study	 African Caribbeans and Black Africans have markedly raised incidence rates (IRR) compared with the White British group for all psychosis. 	reported raised rates of schizophrenia in the African-		
	 Rates are particularly raised for both schizophrenia and mania in African-Caribbeans and Black Africans. 	Caribbean population. The incidence of schizophren		
	■ It is worth noting that African-Caribbeans have a significantly higher IRR than Black Africans	in the Caribbean does not appear to be markedly raised.		
Morgan & AESOP Fearon study 2007		■ Incidence of all psychoses was significantly higher in the African-Caribbean population compared with the baseline White British population (African-Caribbeans: IRR (Incidence Rate Ratio) 6.7 (5.4-8.3)). This difference was most marked for schizophrenia (ICD-10 F20) and manic psychosis (ICD-10 F30-31).	 Used data from the 2001 UK census as the denominator Black African refers to migrants from sub-Saharan Africa and their children 	
	■ In the White British group, 58% experienced persecutory delusions during a first episode of psychosis compared with 70% of African-Caribbeans and 74% of Black Africans.			
	 Prevalence of first-rank symptoms were less common among African- Caribbeans and Black Africans with a diagnosis of schizophrenia. 			
	■ Schizophrenia seemed less 'Schneiderian' in the black than in the white group			
		■ No evidence that any of the more biological risk markers for schizophrenia are more common or have a greater effect in the African-Caribbean population		

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Citation	Study Group	Key results and Interpretation	Comments
Dean et al. 2007		 A diagnosis of mania and the presence of manic symptoms increased risk of aggression Almost 40% (n=194) of the sample were aggressive at first contact with services; approximately half of these were physically violent Younger age, African-Caribbean ethnicity and a history of previous violent offending were independently associated with aggression. 	 Co-morbid personality disorder was not assessed in this study and is a potential interacting factor. Case ascertainment in this study was achieved by service contact rather than a population survey. Selection biases may have been present There were more men than women in the current study, a factor likely to elevate the
Cooper	AESOP	 After controlling for age and gender, people from Black ethnic 	prevalence of aggression in the sample, while the mean age for the sample (31 years) may have had the opposite effect. • A longitudinal study needed to
et al. 2008	study	groups were over four times more likely to have psychosis than White people. The association between Black ethnicity and case status was reduced by controlling for socio-economic factors (social class, educational level, religious adherence, employment) and for greater perception of disadvantage, confirming evidence of mediation, but increased by controlling for self-esteem and self-concept.	determine whether disadvantage, perceived or actual, predicts the emergence of psychosis. Direction of causality cannot be determined from this cross-sectional study.
		 Being younger, unemployed and from a Black ethnic group, expressing adherence to some form of religion and perceiving more disadvantage were the significant factors predicting case status. People with psychosis report more disadvantage than controls after taking account of socio-economic factors including ethnicity. 	
Morgan et al. 2009	AESOP study	 When compared with White British subjects, both Black Caribbean and Black African subjects were more likely to endorse psychotic-like experiences When adjusting for indicators of childhood and adult disadvantage, the association between Black Caribbean ethnicity and psychotic-like experiences no longer held, the association between Black African ethnicity and psychotic-like experiences was only moderately attenuated 	representative as possible of the population from which cases in the AESOP study were drawn. This strategy oversampled those who were more socially isolated and likely to endorse unusual beliefs and perceptual experien-
		 Long-term separation from a parent before the age of 16 because of family breakdown remained significantly associated with psychotic-like experiences When childhood and adult disadvantage were taken into account, the association between Black Caribbean ethnicity and psychotic-like experiences was no longer evident 	ces so may, overestimate the true population prevalence. The PSQ, in not takingaccount of the context within which respondentsendorse specific items, will overestimate the prevalence of psychotic-like experiences.
Reininghaus et al. 2010	AESOP study		
		 The relationship of ethnic identification and psychosis in the BME group was confounded by perceived disadvantage. Ethnic identification may be a potential contributory factor of the elevated rates of psychosis in the UK BME population 	

Fearon et al. (2006), and Morgan & Fearon (2007) compares African Caribbean with Black Africans, a distinction that is clearly needed. The AESOP study determined ethnicity separately and subdivided into Black African and Black Caribbean; Black Other was then grouped with Black Jamaican due to similar incidence rates. This subgrouping is problematic; Africa is a rich continent with many different cultures and beliefs and to categorise Black Africans by the continent and not countries can introduce errors in data collection. A study by Agius et al. (2010) has shown that within the South Asian community there was a different in numbers that suffered psychosis between Bangladeshi and Gujarati people, further highlighting the need for a separation in ethnicity. Although the AESOP papers also assert that the difference in incidence rate of schizophrenia is too great to be due to misdiagnosis, they fail to acknowledge the effect misdiagnosis can yield as a confounding factor, exaggerating what may be a mild increase in rate.

The AESOP study also showed an increased rate of affective disorders in the African Caribbean and Black African population. However, it may be possible that some incidences of psychosis were incorrectly ascribed to schizophrenia instead of bipolar disorder. The AESOP-10 multicentre study (Morgan et al. 2014) is a 10-year follow-up of a large cohort of 557 people with first-episode psychosis initially identified in the southeast London and Nottingham centres of the AESOP study. At follow-up, of the 532 incident cases initially identified, only 219 (41.2%) were re-interviewed; those who had emigrated were more likely to be of black African ethnicity. Without proper follow-up, we cannot be certain that the initial diagnosis was correctly made.

From the 1990s onwards, there was a great deal of debate around issues about cultural sensitivity and institutionalised racism in the diagnostic models in psychiatry. Lewis et al. (1990), found that psychiatrists were less likely to diagnose schizophrenia in African Caribbean men when their ethnicity was made known. However, they also found that psychiatrists were more likely to ascribe a violent stereotype to African Caribbean men. Hickling et al. (1999) showed bias may exist in diagnosis methods, of 29 African and African-Caribbean patients diagnosed with schizophrenia, the diagnoses of the British and the Jamaican psychiatrists agreed in 16 instances (55%) and disagreed in 13 (45%). Agreement between the Jamaican psychiatrist and his UK counterparts about which patients had schizophrenia was poor.

Data in the AESOP may be contaminated by improper collection due to lack of training in interpreting cultural bias. This is supported by the increased prevalence of non-classical diagnosis of schizophrenia, increased religious delusions and aggression in diagnosis in African Caribbean and Black African men. The AESOP study used the Schedule for Clinical Assessment in Neuropsychiatry (SCAN) interview

process (Organisation 1992) to collect symptom data and based the methodology on the World Health Organisation (WHO) ten country study (Jablensky et al. 1992, Kirkbride et al. 2006, Morgan et al. 2006). However, unlike the WHO study, psychiatrists of representative ethnicities were not used when interpreting the interviews, nor was cultural context given for each case. Cultural differences cause differences in societally accepted beliefs which can affect interpretation of delusions – "the difference between insanity and belief is the number of believers." Increased misinterpretation of symptoms may be due to improper training of data collectors. Misdiagnosis may act as a confounding factor when measuring incidence of schizophrenia in African Caribbean and Black African men. Populations were estimated using a consensus that was performed after the interview period. The study population was collected through those who accessed services rather than a population survey which introduces bias into the sample. The study also examined three predominantly urban areas and the findings may therefore not be generalised to other areas in the UK. The conclusions were drawn from patients who had engaged with services. However, it is unwise to extrapolate these outcomes to patients in the general population who have not engaged with services.

CONCLUSION

The increased number of schizophrenia diagnoses in Black African-Caribbean and Black African men in the UK may be due to various social factors, such as immigration status, racial tension and family dynamics. However, there are faults in diagnosis which skew these numbers. In order to reduce the number of misdiagnoses it is important that interviews are aware of cultural differences between ethnicities and are able to apply them accordingly in context. England is a multicultural landscape; multiplicity of cultures makes diagnosis difficult. There is a need for familial and/or cultural input. The lessons we must learn from the AESOP study is the need for transcultural training and the removal of blinding to ethnicity when a large epidemiological study is conducted – psychiatrists need to be cognisant of cultures and aware of the context of symptoms.

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Conflict of interest:

Mark Agius is a Member of an advisory board to Otsuka, Japan.

References

1. Agius M, Talwar A, Murphy S & Zaman R: Issues regarding the delivery of early intervention psychiatric services to the South Asian population in England. Psychiatr Danub 2010; 22:266-269.

- Cantor-Graae E & Selten JP: Schizophrenia and migration: A meta-analysis and review. American Journal of Psychiatry 2005; 162:12-24.
- 3. Cooper C, Morgan C, Byrne M, Dazzan P, Morgan K, Hutchinson G, Doody GA, Harrison G, Leff J, Jones P, Ismail K, Murray R, Bebbington PE & Fearon P: Perceptions of disadvantage, ethnicity and psychosis. British Journal of Psychiatry 2008; 192:185-190.
- Dealberto MJ: Why are immigrants at increased risk for psychosis? Vitamin D insufficiency, epigenetic mechanisms, or both? Medical Hypotheses 2007; 68:259-267
- 5. Dean K, Walsh E, Morgan C, Demjaha A, Dazzan P, Morgan K, Lloyd T, Fearon P, Jones PB & Murray RM: Aggressive behaviour at first contact with services: findings from the AESOP First Episode Psychosis Study. Psychological Medicine 2007; 37:547-557.
- 6. Fearon P, Kirkbride JB, Morgan C, Dazzan P, Morgan K, Lloyd T, Hutchinson G, Tarrant J, Fung WLA, Holloway J, Mallett R, Harrison G, Leff J, Jones PB, Murray RM & Aesop Study Grp: Incidence of schizophrenia and other psychoses in ethnic minority groups: results from the MRC AESOP study. Psychological Medicine 2006; 36:1541-1550.
- 7. Hickling FW, McKenzie K, Mullen R & Murray R: A Jamaican psychiatrist evaluates diagnoses at a London psychiatric hospital. British Journal of Psychiatry 1999; 175:283-285.
- 8. Hickling FW & Rodgersjohnson P: The incidence of first contact schizophrenia in Jamaica. British Journal of Psychiatry 1995; 167:193-196.
- Jablensky A, Sartorius N, Ernberg G, Anker M, Korten A, Cooper JE, Day R & Bertelsen A: Schizophrenia: manifestations, incidence and course in different cultures. A World Health Organization ten-country study. Psychological medicine. Monograph supplement 1992; 20:1-97.
- 10. Kirkbride JB, Fearon P, Morgan C, Dazzan P, Morgan K, Tarrant J, Lloyd T, Holloway J, Hutchinson G, Leff JP, Mallett RM, Harrison GL, Murray RM & Jones PB: Heterogeneity in incidence rates of schizophrenia and other psychotic syndromes Findings from the 3-center AESOP study. Archives of General Psychiatry 2006; 63:250-258.
- 11. Littlewood R & Lipsedge M: Some social and phenomenological characteristics of psychotic immigrants. Psychological Medicine 1981 11:289-302.
- 12. Morgan C & Fearon P: "Social experience and psychosis Insights from studies of migrant and ethnic minority

- groups." Epidemiologia E Psichiatria Sociale-an International Journal for Epidemiology and Psychiatric Sciences 2007; 16:118-123.
- 13. Morgan C, Fisher H, Hutchinson G, Kirkbride J, Craig TK, Morgan K, Dazzan P, Boydell J, Doody GA, Jones PB, Murray RM, Leff J & Fearon P: Ethnicity, social disadvantage and psychotic-like experiences in a healthy population based sample. Acta Psychiatrica Scandinavica 2009; 119:226-235.
- 14. Morgan C, Lappin J, Heslin M, Donoghue K, Lomas B, Reininghaus U, Onyejiaka A, Croudace T, Jones PB, Murray RM, Fearon P, Doody GA & Dazzan P: Reappraising the long-term course and outcome of psychotic disorders: the AESOP-10 study. Psychological Medicine 2014; 44:2713-2726.
- 15. Morgan C, Mallett R, Hutchinson G, Bagalkote H, Morgan K, Fearon P, Dazzan P, Boydell J, McKenzie K, Harrison G, Murray R, Jones P, Craig T, Leff J & Aesop Study Gr: Pathways to care and ethnicity. I: Sample characteristics and compulsory admission Report from the AESOP study. British Journal of Psychiatry 2005a; 186:281-289.
- 16. Morgan C, Mallett R, Hutchinson G, Bagalkote H, Morgan K, Fearon P, Dazzan P, Boydell J, McKenzie K, Harrison G, Murray R, Jones P, Craig T, Leff J & Aesop Study Grp: Pathways to care and ethnicity. 2: Source of referral and help-seeking Report from the AESOP study. British Journal of Psychiatry 2005b; 186:290-296.
- 17. Morgan C, Craig T, Dazzan P, Morgan K, Jones P, Harrison G, Leff J, Murray R, Fearon P & Aesop Study Grp: First episode psychosis and ethnicity: initial findings from the AESOP study. World Psychiatry 2006; 5:40-46.
- 18. Pinto R: A study of Psychiatric Illness among Aisans in the Camberwell area. University of London, 1970.
- 19. Reininghaus U, Craig TKJ, Fisher HL, Hutchinson G, Fearon P, Morgan K, Dazzan P, Doody GA, Jones PB, Murray RM & Morgan C: Ethnic identity, perceptions of disadvantage, and psychosis Findings from the AESOP study. Schizophrenia Research 2010; 124:43-48.
- 20. Siddle R, Haddock G, Tarrier N & Faragher EB: Religious delusions in patients admitted to hospital with schizophrenia. Social Psychiatry and Psychiatric Epidemiology 2002; 37:130-138.
- 21. Wessely S: The Camberwell Study of Crime and Schizophrenia. Social Psychiatry and Psychiatric Epidemiology 1998; 33:S24-S28.
- 22. World Health Organisation: Schedules for Clinical Assessment in Neuropsychiatry. Geneva, Switzerland: World Health Organisation, 1992.

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