

## RUNNING HEAD: ETHNICITY AND CARE PATHWAY

The association between ethnicity and care pathway for children with emotional problems in routinely-collected child and adolescent mental health services data

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**Abstract**

**Background:** Adults from black and minority ethnic (BAME) backgrounds are less likely to access mental health services through voluntary care pathways and are more likely to access through compulsory ones. **Aims:** The aim of the present research was to explore the association between ethnicity and care pathway through child and adolescent mental health services (CAMHS), in terms of reason for referral and case closure, in children presenting with emotional problems. **Method:** A sample of  $N = 11,592$  children from 26 CAMHS was taken from a national routinely-collected dataset (56% female; 7% aged 0-5 years, 40% 6-12 years, 53% 13-18 years, and <1% 19-25 years). **Results:** Multinomial logistic regressions showed that BAME children were consistently more likely to be referred to CAMHS through education, social, and other services than primary care, compared to White British children (odds ratio=1.52-9.96,  $p < .001$ ) and they were less likely to end treatment due to child and family nonattendance (odds ratio=0.59-0.79,  $p < .05$ ). **Conclusions:** Similar to adults, children from BAME groups may be more likely to access child and adolescent mental health services through compulsory than voluntary care pathways.

[181 of max. 250 words]

**Keywords:** CAMHS, emotional disorder, referral, care pathway, ethnic minority, service use

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The United Nations Convention on the Rights of the Child 1989, Article 2 makes it a legal requirement to protect children from discrimination. Equitable access to care is a key domain of healthcare quality (Institute of Medicine, 2001) and a particular priority for services for children and families (Royal College of Psychiatrists, 2013). There is little current evidence about differences in mental health service access and discharge in England for children and young people with different ethnic backgrounds. The present study explores these associations, with a focus on children with emotional disorders, which are associated with poorer access to care (Ford, Hamilton, Meltzer, & Goodman, 2007). Only one in four children with a diagnosable mental health problem accesses treatment and this is lowest for children with internalizing disorders, including anxiety and depression, rather than externalizing disorders (Ford et al., 2007). Focusing on a single problem type when investigating care pathways also facilitates the interpretation of results, as they are less likely to be affected by differences in prevalence of mental health problems across ethnic groups, which is not well understood (Green, 2005).

The National Health Service (NHS) in England is free at the point of use for anyone who is a UK resident (NHS England, 2014). The model of healthcare in the England is such that patients pass through referral filters to reach specialist services, with primary care (especially General Practitioners or GPs) being the predominant gatekeeper (Goldberg & Huxley, 1980; Kleinman, 1980).

Patients from minority ethnic groups may be less likely to access specialist services through this care pathway for a variety of reasons. For example, they may be less likely to be registered with a primary care service (necessary to access services), less likely to seek treatment, or there may be cultural differences in symptom expression leading to misdiagnosis, as some symptoms may show stronger associations with clinical diagnoses in certain cultures than in others (Bhui & Bhugra, 2002; Bhui et al., 2003; Morgan et al., 2005; Richter, Sagatun,

Heyerdahl, Oppedal, & Røysamb, 2011). Referral through primary care may be more likely when the individual is voluntarily seeking help, as opposed to receiving compulsory mental healthcare treatment (Zwaanswijk, Van der Ende, Verhaak, Bensing, & Verhulst, 2005).

In terms of children's mental health, GPs may find it difficult to make referrals to child and adolescent mental health services (CAMHS) generally, and CAMHS referrals from a GP are three times more likely to be rejected than other referrals (Hinrichs, Owens, Dunn, & Goodyer, 2012). CAMHS are comprised of statutory and voluntary services funded through regional commissioning models, providing a range of universal and specialist interventions, in addition to some privately-funded services (NHS, 1995). The most recent public data from CAMHS suggests that there were 107,213 referrals received in 2008/09 (Durham University Mapping Unit, 2009/10).

Evidence suggests that adults from ethnic minority backgrounds are less satisfied with primary healthcare services; in particular, adults from ethnic minority groups have been shown to be less satisfied with referral to specialist services by their GP when they thought it was necessary (Campbell, Ramsay, Green, & Care, 2001). Adults from BAME backgrounds are less likely to access mental health services voluntarily and are more likely to access compulsorily than White British adults (e.g. Bhui et al., 2003; Morgan et al., 2005). Accessing mental health services through compulsory routes may be associated with more enduring difficulties and worse outcomes (Harrison, Holton, Neilson, & al., 1989; McKenzie, van Os, Fahy, & al., 1995).

Compared to the latest national survey of children and young people's mental health (Green et al., 2005), the most recent public data from CAMHS (Durham University Mapping Unit, 2009/10) shows that the demographic characteristics of children attending services with any presenting problem is comparable to those of children experiencing emotional problems, although children in the younger age group may be under-represented. In terms of ethnicity, 77% of children accessing CAMHS for any presenting problem are White British, 3% White Other; 4% Mixed; 3% Asian; 4% Black; with 1% reporting another ethnic identity and 6% not stating an ethnic identity.

Referral source is mainly through primary care (49%), followed by education (12%), social services (12%), child health (14%), and other services (12%).

Children from BAME backgrounds may be less likely to access CAMHS compared to White British children (Dura-Vila & Hodes, 2012; A. Goodman, Patel, & Leon, 2008; Vostanis, Svirydzienka, Dugard, Singh, & Dogra, 2013; Zwaanswijk, et al., 2005). A Swedish study found that older and BAME children were less likely to be referred to mental health services by the family and were more likely to be referred through social or legal services (Ivert et al., 2011). Boys, younger children, and BAME children were also more likely to be referred through schools or other healthcare agencies. An English study found that children from Indian and Indian British backgrounds were more likely to access support through informal pathways such as approaching family members and teachers (Vostanis, et al., 2013). Qualitative studies have found that British Asian families report stigma around mental health and that the fear of gossip is a reason for not accessing CAMHS (Bradby et al., 2007). A number of other studies also suggest that BAME children are less likely to be referred to CAMHS through primary care services than White children (Daryani, Hindley, Evans, Fahy, & Turk, 2001; R. Goodman & Richards, 1995; Roberts & Cawthroe, 1995; Skokauskas, Dunne, Gallogly, & Clark, 2010).

There is less consistent evidence on reasons for treatment termination. Premature treatment termination and appointment non-attendance are major problems in CAMHS (Arai, Stapley, & Roberts, 2014), with some studies reporting 22% do not attend their first appointment (Minty & Anderson, 2004). In the studies cited above, there were reports of no significant associations between ethnicity and attendance of first appointment (Daryani et al., 2001) and reports that, although BAME children were no more likely to not attend their first appointment, they were more likely to terminate treatment prematurely (Skokauskas et al., 2010). Other evidence suggests that children from ethnic minority backgrounds have a shorter treatment duration and are more likely to stop attending before treatment is complete (Miller, Southam-Gerow, & Allin Jr, 2009), although the opposite finding has also

been reported in that ethnic minority status predicted treatment continuation for younger children (Baruch, Vrouva, & Fearon, 2009).

### **Aim of the present research**

The above evidence suggests that children and families with different ethnicities may have different care pathways through CAMHS. Still, to the best of our knowledge, there is no evidence as to whether this is generalizable to services across England or limited to specific samples. The aim of the present research was to explore the association between ethnicity and care pathway through CAMHS, in terms of reason for referral and case closure, in children presenting with emotional problems using routinely-collected national data. Compared to children and families from a White British background, we expected that children from BAME backgrounds would be less likely to engage with CAMHS through voluntary pathways and more likely to be referred to CAMHS through primary care and to prematurely terminate treatment.

## **Method**

### **Participants and procedure**

The current sample was drawn from a larger dataset containing activity, demographic, and mental health outcome data collected locally by CAMHS as part of the Child Outcomes Research Consortium (CORC) (Fleming, Bradley, & Wolpert, 2014). Cases were selected for inclusion using the following criteria: the child came into contact with the service in or after 2007, emotional disorder was recorded as the presenting problem, and the child's record had complete data for age, gender, ethnicity, referral route, and reason for case closure.

The final sample comprised  $N = 11,592$  episodes of care from 26 CAMHS in England submitted between 2007 and 2013. Over half of the sample was female (56%,  $n=6,441$ ), and children were aged between 0-5 years

(7%,  $n=755$ ), 6-12 years (40%,  $n=4,657$ ), 13-18 years (53%,  $n=6,102$ ), and 19-25 years (<1%,  $n=15$ ). The age and gender profile of the present sample was similar to other national figures for children with emotional disorders (Green, McGinnity, Meltzer, Ford, & Goodman, 2005). The measures were taken from a secondary analysis of routinely-collected data so ethical review was not relevant (NHS, 2015).

### **Ethnicity**

Ethnicity was recorded by services using the categories from the 2001 Census and were generally based on self-report by the parent or the young person if seen alone. These were grouped for analysis as follows: White British, Other White background (including White Irish and Other White background), Mixed (including Mixed White and Black Caribbean, Mixed White and Black African, Mixed White and Asian, and any other mixed background), Asian or Asian British (including Indian, Pakistani, Bangladeshi, and Other), Black or Black British (including Caribbean, African, Other), and Other Ethnic group (including Chinese and Other). The most frequently reported ethnicity was White British (63%,  $n=7,185$ ), followed by Asian or Asian British (10%,  $n=1,199$ ), Black or Black British (8%,  $n=883$ ), Other Ethnic background (7%,  $n=828$ ), Other White background (6%  $n=745$ ), and Mixed background (6%  $n=689$ ). The present sample had a lower proportion of White British children (63%), which has been estimated at 89% in previous national data (Durham University Mapping Unit, 2009/10).

### **Referral route**

Referral route was recorded by services using the following categories: education (including schools, education psychologists, welfare officers, and learning support teachers), social services, primary care, child health (including acute and community paediatricians, district nurses, and school nurses), youth justice (including youth offending teams, probation services, legal services, and courts), self-referral, accident and emergency (A&E),

voluntary sector, learning disability services, adult mental health (including community and inpatient adult mental health services), and other service or agency. Referral routes that equated to less than 5% of the total were collapsed into 'other referral routes', which included youth justice, self-referral, A&E, voluntary sector, learning disability services, adult mental health, other trusts, and other service or agency. The referral routes for the sample were referral by primary care (58%,  $n=6,743$ ), education (15%,  $n=1,694$ ), social care services (10%,  $n=1,108$ ), child health (9%,  $n=1,076$ ), and other (8%,  $n=908$ ).

### **Reason for case closure**

Services recorded reason for case closure using the following categories: mutual agreement to end treatment, child/family stopped attending (reason unknown), child/family moved out of area, referred to another service, referred to adult services, and other. Reasons for case closure that equated to less than 5% of the total were collapsed into broader categories; this meant that referred to adult services was grouped with referred to another service and child/family moved out of area was grouped with other. The reasons for case closure of the sample were closure because of mutual agreement (64%,  $n=7,407$ ), child/family stopped attending (21%,  $n=2,405$ ), referred to another service (9%,  $n=1,027$ ), and other (6%,  $n=690$ ).

### **Analytic strategy**

To explore the associations between ethnicity and care pathway in children with emotional problems, we conducted multinomial logistic regressions with ethnicity predicting referral route and reason for case closure. For both referral route and reason for case closure, we selected a reference category against which the other categories would be compared (Field, 2013).

For referral route, primary care was chosen as the reference category as this was the most frequently selected; for reason for case closure, mutual agreement to end treatment was chosen as the reference category as this was the



most frequently selected. Two models were tested for each dependent variable. In the first model, age and gender were included. Age was recorded in bands, categorised as 0-5 years (chosen as the reference category), 6-12 years, 13-18 years and 19-25 years. Gender was coded male (the reference category) and female. In the second model, ethnicity was added to determine whether it explained variance in care pathway above and beyond age and gender and, if so, how ethnicity was associated with care pathway. White British was chosen as the reference category for ethnicity as this was the most frequently selected. All analyses were conducted using STATA (Muthén & Muthén, 1998-2013).

## Results

### Referral route

Table 1 shows the results of the multinomial logistic regressions predicting referral route. Model 1 was significant ( $\chi^2[16]=490.67, p<.001, \text{Pseudo } R^2 = 0.017$ ), and age and gender were both significant predictors of referral route. Children aged 6-12 years were more likely (odds ratio or OR=1.85) to be referred through education services than primary care, compared to children aged 0-5 years; boys were more likely (OR=1.28) to be referred through education services than primary care, compared to girls. In addition, young adults aged 19-25 years were more likely (OR=13.71) to be referred through other services than primary care, compared to children aged 0-5 years. In contrast, children aged 6-12 years were less likely to be referred through social services (OR=0.52), child health services (OR=0.52), or other services (OR=0.37) than primary care, compared to children aged 0-5 years. Similarly, young people aged 13-18 years were less likely to be referred through social services (OR=0.33), child health services (OR=0.30), or other services (OR=0.38) than primary care, compared to children aged 0-5 years.

Adding ethnicity in Model 2 significantly improved the model fit; likelihood ratio test:  $\chi^2(20) = 481.85, p < .001$ . Mixed race children were more likely to be referred through education services (OR=2.47), social services

(OR=4.21), and other services (OR=2.71) than primary care, compared to White British children. Similarly, Asian children were more likely to be referred through education services (OR=2.51), social services (OR=2.98), and other services (OR=2.64) than primary care, compared to White British children. Black children were more likely to be referred through education services (OR=4.89), social services (OR=9.96), and other services (OR=5.45) than primary care, compared to White British children.

On the one hand, children with other ethnic identities were more likely to be referred through education services (OR=1.52), social services (OR=2.63), and other services (OR=3.69) than primary care, compared to White British children. On the other hand, children with other ethnic identities were less likely to be referred through child health services (OR=0.57) than primary care, compared to White British children. Finally, children with a White Other ethnic identity were more likely to be referred through education services (OR=1.53), social care (OR=1.64), and other services (OR=2.21) than primary care, compared to White British children.

#### INSERT TABLE 1

#### **Reason for case closure**

Table 2 shows the results of the multinomial logistic regressions predicting reason for case closure. Model 1 was significant ( $\chi^2[12]=128.25$ ,  $p<.001$ , Pseudo  $R^2 = 0.0056$ ), and age and gender were both significant predictors of reason for case closure. Children aged 6-12 years were less likely to have their case closed because the child and family stopped attending (OR=0.79) or because they were referred to another service (OR=0.74) than mutual agreement to end treatment, compared to children aged 0-5 years. In contrast, young people aged 13-18 years were more likely (OR=1.92) to have their case closed for other reasons than mutual agreement to end treatment, compared to children aged 0-5 years. Similarly, young adults aged 19-25 years were more likely (OR=3.53) to

have their case closed because the young adult and family stopped attending rather than mutual agreement to end treatment, compared to children aged 0-5 years.

Adding ethnicity in Model 2 significantly improved the model fit; likelihood ratio test:  $\chi^2(15) = 44, p < .001$ . Mixed race children were less likely to have their case close because child and family stopped attending than mutual agreement to end treatment (OR=0.78), compared to White British children. On the one hand, Asian children were less likely to have their case closed because child and family stopped attending (OR=0.59) or because of other reasons (OR=0.73) than mutual agreement to end treatment, compared to White British children. On the other hand, Asian children were more likely (OR=1.44) to have their case closed because of referral to another service than mutual agreement to end treatment, compared to White British children. Black children were less likely to have their case closed because child and family stopped attending than mutual agreement to end treatment (OR=0.78), compared to White British children. Similarly, children with other ethnic identities or children with a White Other ethnic identity were less likely to have their case closed because child and family stopped attending (OR=0.79 and 0.76, respectively) than mutual agreement to end treatment, compared to White British children.

INSERT TABLE 2

### **Discussion**

The aim of the present research was to explore the association between ethnicity and care pathway through CAMHS, in terms of reason for referral and case closure, in children presenting with emotional problems using routinely-collected national data. BAME children were more likely to be referred through education services, social services, and other services than primary care, compared to White British children. Children with other ethnic identities were also less likely to be referred through child health services than primary care, compared to White British children. The finding that BAME children were less likely to be referred through primary care than White British children dovetails with findings from previous studies (Daryani, et al., 2001; Ivert et al., 2011;

Skokauskas, et al., 2010). The largest odds ratio showed that Black children were almost ten times more likely to be referred to CAMHS through social care services than primary care, compared to White British children. A number of theories could explain this: ethnic minority parents may be less likely to be registered with a primary care service, they may be less likely to seek professional treatment, there may be additional attitudinal barriers or concerns, or there may be cultural differences in symptom expression leading to misdiagnosis (Bhui & Bhugra, 2002; Bhui, et al., 2003; Bradby, et al., 2007; Morgan, et al., 2005). Another possible explanation might be that parents act as ‘gatekeepers’ to CAMHS along with GPs and their understanding of their children’s illness and treatment options affects their likelihood of referral (Arai, Stapley, & Roberts, 2014).

A recent research trial has shown that interventions to decrease non-attendance in CAMHS are equally effective for White and BAME groups (Michelson & Day, 2014) which may be a useful tool for individual services that discover an association between ethnicity and lower attendance in CAMHS. One review of the literature has cited specialist services for BAME groups, with a focus on collaboration to facilitate referral routes between different services and outreach as key components to improving access to mental healthcare (Moffat, Sass, McKenzie, & Bhui, 2009).

Still, in the present research, BAME children were less likely to have their case closed because child and family stopped attending than mutual agreement to end treatment, compared to White British children. Asian children were also more likely to have their case closed because of referral to another service and were less likely to have their case closed because of other reasons than mutual agreement to end treatment, compared to White British children. Existing literature shows an inconsistent pattern of associations between ethnicity and treatment continuation. On the one hand, studies have reported that children from BAME backgrounds have a shorter treatment duration and are more likely to stop attending before treatment is complete (Miller, et al., 2009; Skokauskas, et al., 2010). On the other hand, studies have reported no significant associations between ethnicity

and attendance (Daryani, et al., 2001) and that ethnic minority status predicts treatment continuation for younger children (Baruch, et al., 2009).

The findings of the present research may be in line with findings from previous studies, that adults from BAME backgrounds are less likely to access mental health services voluntarily and are more likely to access compulsorily than White British adults (e.g. Bhui et al., 2003; Morgan et al., 2005). This may partially explain the high rate of BAME children being referred through social care services and not having their case closed due to non-attendance if they are accessing CAMHS compulsorily under the Children's Act 1989.

Limitations should be considered when interpreting the findings of the present study. The present study used naturalistic, routinely-collected data as opposed to those collected under controlled conditions. Therefore, limitations of confounding variables and selection bias may apply (Gilbody, House, & Sheldon, 2002). Still, demographic characteristics such as age and gender were controlled for in all analyses (see Analytic strategy). The use of the CORC dataset means that there may be variation in how data were collected and recorded, as individual services may have collected and coded information differently. Although the present study was based on a large national dataset including data from 26 CAMHS, findings may not generalize to other CAMHS in England. Similarly, the CORC dataset does not include information on socioeconomic status, and it is possible that BAME children had a lower socioeconomic status than White British children, potentially explaining the associations with reason for referral and case closure; future research should examine whether socioeconomic status is associated with care pathway above and beyond ethnicity. Finally, data were not available to explore reasons for these differences in care pathway, and future research should explore perceptions of service users, service providers, and referrers to help understand the findings of the present research.

Notwithstanding the above limitations, the present study includes the first findings from a large national routinely-collected dataset on the associations between ethnicity and care pathway in children with emotional problems accessing CAMHS. BAME children were consistently more likely to be referred to CAMHS through

education, social, and other services than primary care, compared to White British children, and they were less likely to end treatment due to child and family non-attendance. Future research should continue to explore reasons for these differences to understand the best way of ensuring services are equally accessible to all children and young people.

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