What changes would you like to make to the field of Eating Disorders to help patients and carers better?

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By the time I met Leanne*, I had spent six years tutoring. I had journeyed over 1000 miles and helped more than 70 students. I used to dart between lectures in an attempt to cram in as much business that my cash-poor-medical-student-self could muster. Me, and Flo — my dilapidated Vauxhall Corsa — chugging across the plains of Northern Manchester now seems like a distant memory. These days, I work as an inpatient eating disorders doctor. But when I look back on my time as a private tutor, memories of Leanne are most prominent.

I remember thinking that she was incredibly organised and self-assured. She also wanted to be a veterinary surgeon. I felt she would be a brilliant candidate for this. Not just because the middle-class nature of her upbringing meant she owned two beautiful foals, but because she was incredibly bright. At the time, I knew that veterinary medicine demanded higher grades than medicine. But, the main reason memories of Leanne are hard to shake, was the fact that she was White. Up until that point, I hadn't spent a single second with a White student. My tutees were mainly Black. What was it about me that meant the vast majority of my tutees were Black?

Parents of the typically young, Black boys I had the privilege of teaching, told me they were after a mentor — not just a tutor — for their struggling teens. They believed that success in this mentorship role would be more achievable by someone who looked like their children, had a similar upbringing to them, and was now 'doing well'. Many of these families often lived in council housing and had to contend with low socioeconomic environments which lacked many reference points of academic success. Being the son of two struggling Nigerian migrants to the UK, I could relate with such challenges.

The parents — or often, single parent — of my tutees considered me the last, and most financially expensive, option. A few struggled to afford weekly lessons and worked multiple jobs to raise funds.

The System

Whilst tutoring, I felt exasperated. I was firefighting; desperately trying to help my tutees with gaps in their knowledge. The education system needed to be more robust, but instead it was letting them down. Now, I would never have imagined that all these years later, despite being in a completely different job, that I'd be left feeling the same way. So far, despite working in the eating disorders field for more than two years, I've only treated a few Black inpatients. This is regrettable, because research suggests there are Black people suffering with difficulties with food¹. But the system, as it currently stands, is not conducive to their needs. The net of eating disorders care appears to be too ethnically biased to catch them. Yet again, a system — this time one I feel very much a part of — is letting Black individuals down.

We can help patients and carers better by changing the eating disorders field to improve the care for Black patients, as well as patients from other underrepresented ethnic groups. And I believe we can do this by improving identification, availability, trust and accessibility.

Identification

"He's lost focus and is now performing badly. I saw your profile online. He needs motivation. A Black role model." — Mother of a 15-year-old, Black, male tutee from Gorton, Manchester Firstly, my services were often requested because I was Black. My Blackness offered no guarantee of rapport with my tutees, but it was assumed that I may be able to identify more with their experiences and subsequent challenges, when compared to a White tutor. This may have been flawed thinking, but what it *does* emphasise is the importance of ethnocultural factors. With this in mind, eating disorders services should perform regular **ethnocultural assessments**. These assessments would scrutinise the entire service, screening for any unconscious biases in care.

The notion of ethnocultural biases in the delivery of healthcare is not new. I once had a 50-year-old Black patient who, during her inpatient stay, remained socially isolated on the ward because she deemed the ward activities as being "too White". I had a 26-year-old inpatient who did not find the ward conducive to certain aspects of his cultural and religious beliefs and practices. I also had an inpatient whose psychological therapy was thwarted due to issues with communication (she had recently migrated to the UK and spoke limited English). Eating disorders services need to be more adaptable to ethnocultural differences in order for Black patients to *identify* with its offerings and thus reach out for support.

Secondly, it may prove beneficial for organisations (e.g. Royal College of Psychiatrists) to work closely with Black healthcare workers in the field, as well as patients with lived experience, to increase awareness of eating disorders in the Black community. This can be achieved through **eating disorders workshops**. Such workshops (which research suggests are a valuable resource²) will provide opportunities to challenge misconceptions of the eating disorders services. It would include body image groups and education classes. Encountering other Black individuals at these workshops may encourage some to feel as though they can *identify* more with the service. In turn, they may be more forthcoming with their issues.

The Black individuals with eating disorders that I have spoken to highlight their ignorance in not knowing that their behaviours warranted a diagnosis. So, these workshops would provide a platform to further educate patients and their support networks (this is particularly important because — just as with my tutoring — the individual's support network is often heavily involved).

Availability

"We're flexible and can work around you. I'll finish work early and pick him up from school." — Mother of 17-year-old, Black, male tutee from Hale, Manchester

Availability is a two-way street. A tutee may have been ready and available to have lessons, but if *I* wasn't, then that was the end of that — and vice versa. Our *availability* as an eating disorders service needs to be examined. Inpatient eating disorders services are bereft of beds. So the question arises, 'even if there was Black engagement, would an inpatient bed be available?' In Germany, as a way of promoting equity, a percentage of newly-built homes are reserved for disadvantaged individuals. Likewise, in eating disorders services, a temporary **quota of care** should be considered. This would ensure a percentage of inpatient beds were prioritised for those from underrepresented ethnic groups. This would hopefully propagate Black individuals to seek care when needed.

The lack of research on the intersection of eating disorders and the Black community is staggering³. There needs to be, as a starting point, a **research and data gathering strategy**. This would interrogate the *availability* of eating disorders services nationwide, providing data to inform future location- and demography-specific operations. When I had a new tutee, I would typically start by gathering data about them. This is very much a similar notion. It would follow in the footsteps of organisations such as the NHS Race and Health Observatory, which recently bolstered its equality and diversity research⁴.

Trust

"He's gained so much confidence in Maths! He doesn't want to show it in front of his friends but he's doing a lot better at it." — Mother of 16-year-old, Black, male tutee from Gorton, Manchester

Firstly, my tutees had to trust *me* — the individual. There is a historical distrust of the mental health services by members of the Black community. In this year's Commission on Race and Ethnic Disparities report⁵, it highlighted a reluctance in the Black community to admit mental health issues due to a lack of confidence in the system and fears "of being classed and treated on the basis of a stereotype". The eating disorders services should work with other psychiatric specialties to create a **trust campaign** (with a catchy hashtag, e.g. #TrustTheTeam). In many ways, it would resemble the widely recognised #hellomynameis campaign which fought for more compassionate patient care⁶. It would be a campaign featuring affirming statements from Black people from all walks of life (e.g. "I'm [name] and I trust the mental health services"). Seeing Black individuals placing their *trust* in the services, may lead others to follow suit.

Secondly, my tutees had to trust in my ability to deliver for them. Black people need to believe that the care received in eating disorders services will be effective. An annual **Black mental health success report** would provide an amalgamation of the eating disorders success stories of patients from underrepresented ethnic groups. As with my tutoring — where my tutees spoke to others about my involvement in their exam successes — in the world of eating disorders, successful outcomes need to be shared. Research says that Black individuals frequently hide their mental ill health from other members of the family due to stigma⁷. With these success stories, they may be more likely to *trust* the services, and become more open, if they know that the outcome of their care may be positive and lead to recovery.

Accessibility

"£10?! Are you sure? In that case, I'll book ten lessons now if that's OK?" — Father of 14-yearold, male, Black tutee from Wythenshawe, Manchester

A colleague and I were discussing a case where a young Black girl (CAMHS eating disorders inpatient) was discharged despite being very unwell. On reflection, this was likely due to her body being naturally bigger (a higher BMI). As a service, staff need **body and nutrition education classes**. Such classes would seek to explain different types of nutrition that exist in different ethnocultural groups as well as different body types and their respective, evidence-based BMI ranges. In the above example, the service was available but not fully *accessible* to the girl, because of the ethnocentric care she received. Eating disorders services need to decolonise its White body standards to improve access.

When I tutored, I made sure to keep my prices low because most of my tutees were from poorer neighbourhoods. Eating disorders services should be more proactive in taking into consideration the variety of drivers behind illness, including finances. For example, food security issues disproportionately affect those from underrepresented ethnic groups. As it stands, benefitting maximally from inpatient care is financially *inaccessible* for some. For example, repetitive home leave can help with a smooth transition on discharge, however this can be prohibitively expensive; community trips are a key part of normalising eating, but these can be costly if attended regularly; and visits from friends and family can help patients manage the many stresses of inpatient care, however many families are unable to afford the copious amounts of travel. This creates inequitable care, and so the creation of a **care collection** would help to mitigate this. A monetary collection of voluntary donations from members of the public and healthcare workers would help fund certain patients' expenses and help improve all-round access.

The Future

The faith that members of underrepresented ethnic groups have in the eating disorders services is heavily predicated on the level of faith in the mental health services as a whole. So it's important that eating disorders services recognise this and work collaboratively with other psychiatric specialties when necessary, and not in isolation.

Also, many of the above proposed changes rely on social proof (the idea that people copy the actions of others in a given situation). It relies on Black people talking to one another, whether it be a clinician talking to a patient, or patient-patient interactions. Positive influence between members of the Black community is key here.

All in all, a more tailored approach is needed to properly engage members of the Black community — patients *and* carers — in the eating disorders services. Action and energy is required to help upgrade the current system. It is vitally important for Black patients to perceive the eating disorders services differently. They need to know that normative Blackness can co-exist in an eating disorders service, and that any perceived incompatibility is misguided.

*Name changed for anonymity

References

- 1. Taylor JY, Caldwell CH, Baser RE, Faison N, Jackson JS. Prevalence of eating disorders among Blacks in the National Survey of American Life. *Int J Eat Disord*. 2007;40 Suppl(Suppl):S10-S14. doi:10.1002/eat.20451
- 2. Ørngreen R and Levinsen K, "Workshops as a Research Methodology" *The Electronic Journal of eLearning* Volume 15 Issue 1 2017, (pp70-81) available online at www.ejel.org
- 3. Sala M, Reyes-Rodríguez ML, Bulik CM, Bardone-Cone A. Race, ethnicity, and eating disorder recognition by peers. *Eat Disord*. 2013;21(5):423-436. doi:10.1080/10640266.2013.827540
- 4. NHS Race and Health Observatory. Available from: https://www.nhsrho.org/news/invitation-to-tender-development-of-an-interactivedigital-platform-on-ethnic-health-inequalities/ [Accessed on 08/10/2021]
- Commission on Race and Ethnic Disparities: The Report. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachm ent_data/file/974507/20210331_-_CRED_Report_-_FINAL_-_Web_Accessible.pdf [Accessed on 08/10/2021]
- 'Hello, my name is ...': an exploratory case study of inter-professional student experiences in practice. Ban S, Baker K, Bradley G, Derbyshire J, Elliott C, Haskin M, MacKnight J, and Rosengarten L. *British Journal of Nursing* 2021 30:13, 802-810
- Shefer G, Rose D, Nellums L, Thornicroft G, Henderson C, Evans-Lacko S. 'Our community is the worst': the influence of cultural beliefs on stigma, relationships with family and help-seeking in three ethnic communities in London. *Int J Soc Psychiatry*. 2013 Sep;59(6):535-44. doi: 10.1177/0020764012443759. Epub 2012 May 15. PMID: 22588248