ISSN 2380-727X

PSYCHOLOGY AND COGNITIVE SCIENCES

Open Journal

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Perspective

Call for a 'Live Third': The Impact of Institutional and Psychiatric Racism on Adebayo's Physical and Mental Health

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Article information
Received: July 22nd, 2020; **Revised:** August 27th, 2020; **Accepted:** September 3rd, 2020; **Published:** September 14th, 2020

Cite this article
Canepa-Anson A. Call for a 'live third': The impact of institutional and psychiatric racism on Adebayo's physical and mental health. *Psychol Cogn Sci Open J*. 2020; 6(1): 25-30. doi: 10.17140/PCSOJ-6-156

ABSTRACT

The author refers to a personal experience and feels it important to do so in order to highlight a crippling and appalling inhumanity by some towards black people. Much of what is written here is presented in the first person owing to the personal nature of the narrative. It manifests through stereotyping, stigmatisation, and racism towards non-white people. Racism is both institutional and interpersonal, and it is endemic. What gets played out in society is often repeated at an individual level. As a psychotherapist, the author affirms the need for clinical practitioners to move from a position of dismissal and objectification of Black lives, and to wake up to the terrifying fact of the early mortality of black people's lives from the trauma of racism which is very much imbedded in institutional policies and procedures.

Keywords
Black people; Trauma; Mental health; Psychiatric racism; Schizophrenia.

'A 'live third' — the presence that exists between the experience and its meaning'…. the 'live third' is the "other" that creates the possibility of processing the effect of the trauma.[1]

On the 4th of October 2017, I received a shocking call from the Coroner's office to say Adebayo, my youngest brother was dead. Adebayo died on the 29th of September 2017. As next of kin, I was not informed for three days. The cause of death was said to be schizophrenia. He was 41. This was both shocking and devastating to me. This appalling dismissal and total disregard for his life is what has prompted the need for me to document what happened.

Here is His Story

Adebayo was a gentleman. He was kind, tall, and handsome. He was boyish in appearance charismatic and easy to get along with. He was easily liked because of his gentle nature. He was witty, sharp and intelligent. He was generous and compassionate. As a young man, he excelled in most things effortlessly. He was in a choir, wrote poetry, was good at swimming, running, long jump, and hockey, and played the violin. He was a high achiever and a good all-rounder and admired for his versatility. When Adebayo laughed, I thought the world smiled with him. He was easy to love, and he had such a sunny smile. Even though I didn't hear him laugh as much over the years, I remember his smiles.

Growing up, Adebayo was the youngest of three brothers and a sister. He was doted upon. He was fun and charming to be around.

Adebayo was educated in a private boarding school in the UK and was a second-generation British black, born in Nigeria. He came to the UK at age three with his family. He went to boarding school for his primary and secondary education, returning home during the holidays. However, he didn't like the experience, but he made friends and had an active social life. He was grateful for his two brothers, who also attended the same school.

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During his teenage years, at the age of 14, Adebayo's mother was killed. The loss was immense for the family. I feel the impact was more severe for Adebayo as he was the youngest, and was in his adolescent years. Rather unfortunately his father, (my stepfather) was not available to care for him. Adebayo and I lived together for part of the time he survived this period the best way he could, immersing himself in his social life of clubbing, music, going out, and drug taking, no different from any of his peers. Adebayo seemed to have coped up until age 18 or 19, but in his second year at the university, he became depressed and returned home to his father at which time he began to develop panic attacks, agoraphobia, and nightmares.

In his 30s and up until his death, Adebayo's main passion became his music. He collected vinyl, taught himself to compose, and made acoustic music, this became his main outlet.

Adebayo's older brother by two years described him as "*a remarkable student, sort of like a politician, winning people over with his wit and avoiding conflict by diplomacy*". Adebayo's dream was to settle down and have children. He struggled and fought against the 'illness of schizophrenia' for over 20-years.

Medical Intervention or Experimentation

Adebayo was first sectioned (this is when a person is detained under the Mental Health Act 1983 against their will, admitted to hospital, and given treatment, because they are perceived to be a threat to themselves or others).[2]

He was 18, and was immediately diagnosed with schizoaffective disorder. Adebayo complained of pain on his tongue. That pain I believe was linked to early separation and trauma of loss. Background history wasn't taken up and rather unfortunately, his treatment did not encourage family involvement as part of the recovery process, and the family were not privy to his treatment plan. The hope for Adebayo was that another would be capable of bearing the unbearable and be able to make sense of his external and psychic realities and help him integrate the two. Gerson described it is as 'the attuned affective responsiveness' of the other.[1]

For Adebayo, what transpired was that the necessary support was consistently missing and Adebayo was surrounded by indifference, marginalised and devalued for the majority of the time he was the care of support workers, doctors and psychiatrists. This daily attack on self, especially in an environment where one is dependent on the "other" for support, impinges on the psyche, chips away at the self, and is enough to drive one mad; which I believe is what happened.

Psychiatry comes closest to the police among medical specialties in pursuing practices and procedures that explicitly discriminate against minority ethnic groups in the United Kingdom. Evident in the disproportionate numbers of black people in psychiatric detention,[2] and in the misdiagnosis of schizophrenia within the black community. Black people are excluded from the "softer end" of psychiatric practice because they are deemed psychologically unsuitable.[3]

History of Events

In 1999 at age 20, Adebayo was hospitalised under section 2 of the Mental Health Act and admitted to Edgware Hospital, London with a diagnosis of paranoid schizophrenia. He was immediately treated with Olanzapine, (Zyprexa). No background history was taken, and medication was preferred over psychological intervention.

From 2002 until 2017, Adebayo was treated with Olanzapine (Zyprexa), then Clopixol, (Zuclopenthixol) depot, and later Oral Risperidone and Clopixol (Zuclopenthixol) because he complained of constipation.

In 2003, he was treated with Risperidone 37.5 mg depot, 4 mg Chlorpromazine (CPZ)) and Carbamazepine 100 mg bid. His doctor felt that the mood stabiliser helped him greatly but failed to see the severity of the side effects.

In 2004, he began to show high anxiety at any changes in his routine becoming anxious about any physical symptoms. Adebayo was diagnosed with Obsessive Compulsive Disorder (OCD), his symptoms were paranoid thoughts, inability to focus, eye rolling, food intolerance, and sleep intolerance, inability to sleep, hallucinations, and refluxes.

In 2005 at the age of 29, there was the first mention of timelines and counselling, and it was reported that Adebayo was able to talk about his mother's death, his guilt at not mourning that, his present illnesses, and other illnesses that affected his life. This could not be investigated further, and I believe it was already too late; as he was not able to trust in the care that was on offer.

In 2008, he began to display symptoms of panic and agoraphobic symptoms.

In 2010, Clozapine was immediately increased to 300 mg, and Sodium Valproate was introduced at 1.2 g.

In 2012, there was intervention by the crisis team. It was reported that he started showing psychotic symptoms, after he expressed thoughts of being watched. Clozapine was increased to 350 mg.

In October 2015, Adebayo was experiencing: ongoing anxiety, rumination, obsessive thoughts, compulsive behaviour, and feeling compelled to throw out food due to contamination. Clozapine was increased to 400 mg to see if it improved his symptoms even though he said he was scared and, as a result, struggled to take Clozapine at night due to nightmares and lack of sleep.

From May to June 2016, Adebayo started calling the Samaritans.[4]

He accepted that medication was the way forward as this

was what his family were told was the way forward for Adebayo. At this time he lived independently. He was isolated and lonely. He said that the only thing that may help was to live in supported accommodations where a "responsible person" gave him his medication.

From September to October 2016, he began to contact the out of hour's crisis team frequently. On the 11th of February 2017–evidence of further deterioration in Adebayo's mental state was reported. He was reported to have agitated, thought disorder. His doctors started him on Olanzapine and Sodium Valproate as there was no reported improvement in his mental state. His Clozapine level was increased to 400 mg, and his medication on discharge was 250 Clozapine, 450 mg Nocte, and Sodium Valproate 2 g Nocte. On the 13th of July 2017, Adebayo was awaiting a place for supported housing. On the 1st of Aug 2017, he moved to Southwood Smith House in London, a supported housing.

On the 16th of September, he met with his support worker. He reported ongoing issues with a neighbour, who he shared a flat with and who was an avid marijuana smoker. Adebayo had given up cannabis and was trying to eat well and look after himself. Yet the supported housing he was in and his flatmate was an avid marijuana smoker. Adebayo had reported that "*this gentleman had mental health difficulties*". The environment contributed to his ill health.

Adebayo requested further psychological input. An appointment was made on the 29th of September 2017. Adebayo died on the 27th of September 2017. He was 41. In the month before he died, he reported he felt stuck and struggled to see how he might move forward with his life. This sense of helplessness and hopelessness we all carried as a family.

> Gersie[5] stated that *"when talking does not get people anywhere, when tears are exhausted and rage is paralyzed, they cease to exercise authority over the events of their life. Devoid of authorship, deprived of agency and filled with a pervasive sense of helplessness, the person refrains from speaking their mind… thoughts about their reality, and the consideration of possible actions to change that reality, are not understood as problems to be explored. On the contrary, both the situation and the way of life are accepted as inevitability, necessary given in a world out of which there is no escape and beyond which no possibilities can be perceived".*

Adebayo's explained that he couldn't see a way out in the last few months before his death, sums the inevitability of his predicament. The police report said he was cold to touch, and it was difficult to know how long he had been lying dead. The coronary diagnosed the cause of death as schizophrenia. The account given by the consultant psychiatrist and the toxicity report was difficult to read, let alone digest. I spent a month trying to investigate what happened to Adebayo, attempting to speak to the housing manager where he resided, his social worker, psychologist, psychiatrists, crisis team, team manager, doctors. There was a disregard and/or dismissal of my inquiries, and within a week, I was beginning to feel I was the problem. It felt like his life did not matter. This I found painful, confusing and frustrating as his life mattered to me.

The Impact of Stigmatisation and Racism on Adebayo's Mental Health

There is neglect and disregard for people struggling with the so-called illness of schizophrenia in mental health institutions. Zinkin,[6] explained that the environment and persons available in these mental health institutions often reinforce and mirror the psychopathology expressed in the patients' unconscious fears. Adebayo was not ill in the way he was diagnosed. He kept saying the medications were not helping and as a result he was reluctant to take them. He also spoke about the seriousness of the side-effects of the medication. His family were told by the social worker that his symptoms were because he wasn't taking his medication. It was obvious the medication was not helping. We however, hoped he would be believed and be offered what he needed. Adebayo was very astute and aware of what was going on. He was desperate to get help but this help was not forthcoming. The two things he complained about were the medication and the lack of support. He often said that that "*the support staff didn't care*". This position of desperation and hopelessness is what we all shared as a family. Adebayo was disrespected, dehumanised, and overmedicated and medication continued to be the preferred option.

The antipsychiatry movement advocates that conventional psychiatric treatment often isn't in the best interest of the patient and questions whether mental illnesses are actually illnesses at all. Psychiatry has no scientific basis for any of its treatments or methods.[7] We would have to redefine who and what is seen as normal and on what basis are psychiatrists diagnosing people? It was in Adebayo's second year at University reading Business Administration at Leicester in March 1998 that he became increasingly preoccupied with the pain in his tongue, which he said had become overwhelming. He was unable to study. He tried to restart but felt depressed and dropped out. In October 1998, he developed panic attacks, agoraphobia, nightmares and began hallucinating. He was admitted to Edgware hospital on section 2 with a diagnosis of paranoid schizophrenia. This would have been a time for therapeutic intervention but none was on offer and this a consultant questioned why he wasn't responsive to the psychological intervention/s offered 8-years after he was diagnosed and institutionalised. Giving him the label paranoid schizophrenia meant no other avenues could be sought.

After Adebayo's death I decided to investigate about the diagnosis of schizophrenia and its link with psychosis. I found out through attendance of a workshop at the *Hearing Voices Network*[8] that if one is experiencing psychosis this is not necessary a sign of an illness. It was helpful to get this confirmation as this is what I felt all along. Adebayo was trying to tell of his experience of how he perceived the world given his experience of the trauma both of loss and trauma caused by systemic and institutional racism.

The workshop confirmed that hearing voices is a symptom of many different conditions. Sometimes, it can be a fleeting phenomenon with little significance or a general statement of distress, and it shouldn't mean a diagnosis of schizophrenia. In the early days, Adebayo reported hearing voices. The voices were

benign. The voices were from people he trusted who would take care of him. Evidence was a wish to be listened to, respected and giving the necessary care. I do not feel it is too much to expect that people in care should receive care by health practitioners but at the very least not cause any more pain to their patients.

Biologists believe that schizophrenia is biological and link its cause to a chemical imbalance or the result of synthetic drug use. However, today, there is still no scientific evidence as to the cause of schizophrenia.[7] What has become evident is the level of psychiatric misdiagnosis of black men and that structural and interpersonal racism is rife in mental health institutions and severely disadvantages ethnic minorities, and significantly affects their health outcome. They are treated differently to white people; they are often treated inhumanely, disrespected, disregarded, and misdiagnosed. Black lives in this situation don't matter. It is far harder for a person of colour to recover under these circumstances.[9]

The Hearing Voices Network forum, believes one can become mentally ill as a result of extreme stress or trauma, and this can be a part of the root cause of the illness of schizophrenia. Someone experiencing schizophrenia can have a psychotic breakdown. Psychosis is a breakdown or malfunction of repression. If, for whatever reason, the repressed or unconscious memory is no longer unconscious and floods the conscious memory, then that common reality is becomes confusing. This can be brought on by periods of isolation which Adebayo experienced.

In the absence of a mother or a father, one would expect a receptive other would have been helpful. The mental health institution became replacement parental figures as when Adebayo became 18, they took over responsibility for his care. Trust and hope was placed in the doctors, psychiatrists, social workers, psychologists and care workers. One of the challenges and a reality for black men is that they are perceived to be more dangerous and violent in a world where white people are the majority. A lethal response is considered first to deal with the physical symptom in the form of stronger medication (this is borne out of fear,) before dealing with and recognizing the mental health symptoms.[10] Adebayo was reported to "*be violent, appeared threatening and intimidating and appeared suspicious and paranoid*". What actually happened, was Adebayo was trying to defend himself as he was pinned down by the staff on first admission. He was resisting medication. I know Adebayo was not a violent man as they had described.

According to research, black men are over-diagnosed with schizophrenia at least five times higher than any other group—a trend that dates back to the 1960s.[10] In the UK, the incidence of schizophrenia was found to be significantly higher in black Caribbean people than in the white British population. The contributory risk factors appear to be a combination of social and psychological factors, which result in particular vulnerability to the development of schizophrenia.[10] Not much has changed years later, according to UK government website, Ethnicity facts and figures statistics in 2017. Black men are shown to experience a mental disorder in the form of psychosis the highest of all ethnicities.[11] Adebayo was reported to have delusion, paranoia, persecutory thoughts, ruminating thoughts, and more. No thought was given to his past experiences. He would have been better supported if he had been thought of as being fearful, anxious, stressed, not trusting of people, lost to depression, and over thinking.

Schizophrenia has become exemplary of modern-day types of insanity.[12] Given Adebayo's experience what feels insane is to expect compliance with psychotic medication, which in Adebayo's situation only served to supress and confuse. Adebayo on several occasions said the medications was giving him nightmares and other bodily symptoms which finally led to the loss of functioning. The care that people experiencing psychosis receive is usually poor and adds greatly to their distress, worsens their outcome, and leads to their early mortality, according to recoveryinthebin.org.[13] The wards are frightening places. I visited Adebayo there often, and the staff are overwhelmed, often lock themselves away, and are unable to provide basic support. Medication is prioritised over psychological intervention. The patients are being asked to justify why they are unwell through laborious form filling. Policy and decision makers frequently equate their illness to social dysfunction and pathology. Blame is put back on the victim. In this way, the perpetrator is free from addressing their part in it. The most common symptom that researchers believe contribute to misdiagnosis of schizophrenia is hearing voices as almost all incorrectly diagnosed patients reported auditory hallucinations.[14]

Pathways to Mental Healthcare

Racism permeates our economic, social, and political strata. Its impact and stresses contribute to ill-health and for some, admittance into psychiatric services. Unfortunately, people of colour fair worse with misdiagnosis in psychiatry. Factors, such as economic inequality, discrimination, loss of rights, and unstable housing, are contributory factors. Recovery, according to recoveryinthebin.org, identifies that it cannot be a one-size-fits-all and that some people will not feel recovery is possible.

In the UK, doctors, psychiatrists, and nurses are well-trained, but they are often under enormous personal strain from unrelenting pressure of work. This makes it difficult to pay individual attention to each patient. Doctors and psychiatrists are also made to work in tight time slots, and, as a result, they are unable or unwilling to get too involved. The high rate of turnover and locum workers also makes it difficult to receive any consistency or continuity of care. Doctors get paid to sell a particular drug. This can lead to a danger of giving up on very ill patients and treating them as guinea pigs. They can tarnish all patients with the same brush by developing an attitude, a false belief that the patient cannot be helped and cannot get any worse.

Today, the number of people seeking mental health support is worsening. This is evident from the numbers that are on a waiting list. There is a shortage in the number of trained and experienced doctors and psych professionals to meet the growing demand. Some support workers are often not adequately trained and are scared of being 'contaminated' by becoming 'mad' like the patient. As a result, the patients are dehumanised, and those doing the dehumanising justify their attitude by treating the patients as

less than human as a way of not feeling guilt.

There is a high representation of black as compared to white people in the healthcare system needing help. The expertise in care is not growing at the same rate. There are not enough trained black psychiatrists and doctors and other psych practitioners to meet the high proportion of ethnic minorities needing care. Keeping up with regulations in these professions is no longer a requirement, and keeping up with new regulations can be done online and is left to the individual. As a result, supervision is not a pre-requisite in some clinical work. Supervision, which is an integral part of the work, is being side-lined or not made compulsory.[15]

As a community of people, we need to more effectively address these disparities and not simply pay lip service to them. Diagnosis is too dependent on personal (subjective) judgement. It seems too easy to prescribe medication, and practitioners are not adequately held accountable for their actions. A more inclusive quality of care requires improved data systems, increased regulatory vigilance, and new initiatives to appropriately train medical professionals and recruit more providers from disadvantaged minority backgrounds. An inclusive quality of care should include the patient's wider social network, like family and friends.

Paola Leon, a practising psychiatrist of 25-years reminds that, "*Life can be difficult. But we have started to diagnose certain reactions and behaviours as 'mental illness' when, though painful, they are, in fact, part of the human condition*".[16] Psychiatrists have a frightening amount of power at dispensing lethal anti-psychotic drugs. They have the power to decide someone is mentally ill and the power to lock them up against their will.[17]

Challenge for Psych Professions

The psych profession is predominately middle-class, white, and Eurocentric. The white practitioner is tasked to be aware of cultural differences and be aware that often a black person's problems are linked with the racism of the white dominant culture. That poverty, deprivation due to lack of opportunities, exclusion, and a sense of being marginalised, is a reality for most black people. The patient is looking for recognition and acceptance when what he often finds is an objectification. Being able to move from objectification to connecting with another without fear of being taken over is what is required to help some of our patients who are deeply distressed.

The modern-day definition of schizophrenia is a form of madness. My understanding of Adebayo is that he was not ill in the way he was diagnosed. He was in touch with his unconscious and conscious thinking which made him quite vulnerable. He knew a lot about our world and didn't have time for trivialities. He didn't take his experience of being in the world for granted unlike most ordinary people who do not reflect on their basic existence or being.

Adebayo experienced trauma of racism, which expanded the other trauma in his life of the loss of his mother. This loss is a form of melancholia, a sadness which you cannot put words to but is located somewhere in the body and mind. A social worker, who got in touch and befriended Adebayo, said he often looked sad. In health, most people of colour can survive the impact of racism. If you are young and have witnessed irreparable trauma, with limited coping resources, and dependent on the other, then the hope is to have an attuned other, in the absence of this as with Adebayo, and countless others in the psychiatric institution, the journey is often perilous.

What remains shocking was the callous disregard for Adebayo's welfare on the part of the doctors, psychiatrists, support workers, and social worker. Even after his death, the disregard for human life continued. The racism and dismissal I encountered in an attempt to get in touch with those responsible for his care and those people around Adebayo before his death, the consultant doctors, psychiatrist, psychologists, social worker, housing manager, made the despair I felt in the space of a week, unimaginable. I was made to feel I was the problem. When all I wanted to know was what happened to my brother. I can't imagine how those that are more fragile or less supported, endure this on an ongoing basis. It is difficult to believe that so many experienced people could have been so reckless and dehumanising in caring for someone that depended on them. Staff within these institutions find it difficult to understand that they act in ways that have racist effects. They often want to blame the victim for making the wrong choices without acknowledging inequalities and their own internal racism.

CONCLUSION

A recognition of the problem created by racism and psychiatric misdiagnosis and its manifestation is essential. Psychotherapists and other psych professionals, will soon be working with the next generation, the generation of children of refugees, asylum seekers, and migrant families. Trauma in the form of multiple losses, stresses, abuse, and physical and emotional molestations as well as socioeconomic factors, education, fear, and anxiety will influence disease development. Instead of waiting and treating complex personality disorders as psychiatric disorders, often unsuccessfully, early therapeutic intervention would offer an opportunity to prevent psychiatric disorders.

We can provide adequate and supportive environments and not further traumatise the already traumatised. Disorders that have genetic and environmental components, often have more to do with colonisation, wars and conflict torn countries as a result of trans generational transmission of oppression, manifest as stress and anxiety disorders. They have a better chance of a cure with early therapeutic intervention as early as the trajectories towards disease will not yet have been established.

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