

## **Medicine for all - contemporary recommendations for action**

### **"Why Morbus Bosphorus has no ICD-10 code"**

by Gülcan Cetin

Short biography:

Gülcan Cetin is a web video artist for the publicly funded YouTube channel "Datteltäter". With her passion for acting, she breaks down prejudices in a humorous way by refuting common clichés about Muslims in Germany. Away from the camera, Gülcan is a medical student at the Charité and a scholarship holder of the Avicenna Studienwerk. Before her studies, she trained as an operating theatre assistant.

#### **1. What is the problem?**

During treatment in medical institutions, including a visit to the family doctor, the patient's symptoms are summarised into a clinical picture and a diagnosis is made. Each disease is coded using a globally recognised, standardised system for classifying medical diagnoses in so-called ICD-10 codes (International Classification of Diseases, 10th Revision code). These codes are used to classify diseases and other health problems for various purposes, such as reporting medical claims, statistical analyses or in research. They are also used for the billing of medical services, for the compilation of statistics and for quality reporting by hospitals. The current versions of the ICD codes are published by the World Health Organisation (WHO).

The ICD-10 system is currently used in 27 countries and since 2003 has formed the basis for the billing of healthcare services in various countries, including Germany, with the aim of creating a means of controlling costs. In conclusion: No code? No diagnosis! No money!

It is not a rare phenomenon that doctors from the global North in particular have difficulties in making a concrete diagnosis for BIPOC patients or people from the global South. The reported physical complaints cannot always be summarised into a clear diagnosis. The reasons for this vary. Sometimes the patient's appearance is enough to declare them a "difficult case". Some BIPOC patients report that their pain is not "taken seriously" at all or that their pain intensity is considered "exaggerated" and downplayed. The current report of the National Discrimination and Racism Monitor (NaDiRa) from 2023 contains the sub-study "Racism in medical training - a participatory-exploratory analysis" by Hans Voigt. Among other things, it found that just under one in three BIPOC who were labelled racist stated that their complaints were not taken seriously. The study also analysed the extent to which people avoid going to the doctor as a result. For example, 13% to 14% of black, Asian and Muslim women stated that they had delayed or completely avoided treatment for fear of further discrimination. Those affected are attributed an oversensitivity to their pain and the credibility of their physical complaints is denied. Their needs are overlooked. As a result, patients not only lose trust in their doctors, but also do not receive health care comparable to that of white patients.

Due to language barriers and inadequate communication skills as well as insufficient consideration of ethnic and cultural differences, seconded doctors from the global North who work in the global South cannot directly assign the patients' reported pain to a clinical picture or really understand the pain intensities of those affected and therefore make the misdiagnosis of "Morbus Bosphorus". The consequence of this is that the somatic pain, i.e. the pain that is actually physically perceived, is relativised. This increases the suffering of those affected all the more.

Post-operative aftercare, i.e. when patients are hospitalised for an operation and have undergone surgery, for BIPOC patients, can be different in comparison to white patients. Post-operative aftercare, i.e. when patients are hospitalised for surgery and have undergone surgery, for BIPOC patients may well be different in relation to white patients and pose a challenge for globally equitable healthcare in North-South contexts.

BIPOC patients can have different individual perceptions of pain after an operation. If this is not taken into account, those affected will not receive appropriate treatment for their pain. It is assumed that cultural differences in competence and health manifest themselves in the area of post-operative pain management, which points to the need for customised approaches for patients in the Global South.

The historical interpretation of medicine that is critical of racism indicates that for centuries, doctors from the global North shared the erroneous assumption that Black people in particular had less sensitive nerve endings than white people. This topic is discussed in more depth in the text "Medicine for All?" by N'Joula Agnes Baryoh and Ngozi Odenigbo (from the Black in Medicine Collective). Furthermore, historically, medical practitioners in the Global North believed that Black patients in particular had "thicker" skin than white people. These false beliefs and prejudices can contribute to patients from the global South, especially Black people, being attributed a significantly lower perception of pain compared to white people. As a result, patients do not receive adequate medical analysis.

Other factors such as socio-economic status, gender and ethnicity also influence post-operative pain management. Inadequate accessibility, poor communication and cultural aspects have now been identified as barriers to post-operative care, leading to lower satisfaction with surgical outcomes and, consequently, increased complications. Cultural differences and language barriers can have a significant impact on patients' experiences during rehabilitation, so patients are readily referred to other colleagues who are familiar with 'the same' culture.

Language and communication are a major barrier to care, as therapists cannot be sure that patients understand the instructions or goals of the therapies.

Morbus Bosphorus, also known colloquially as "Mediterranean syndrome", should not be confused with familial Mediterranean fever, which is a hereditary disease. Those affected suffer from recurring fever attacks at intervals, accompanied by severe abdominal pain or chest pain, as well as joint pain or skin symptoms. As this hereditary disease is particularly common in the eastern Mediterranean region and mutations in the MEFV gene on chromosome 16 have been confirmed by genetic testing, the "origin" of the disease gives it its name and should therefore not be considered racist. Bosphorus disease, on the other hand, is not a recognised medical term and is therefore not listed in the ICD-10 coding system. It seems to be used informally to describe a perceived phenomenon by medical professionals in which people from the Mediterranean region, e.g. from Southwest Asia and North Africa (SWANA region), are unable to adequately articulate their physical complaints due to language barriers and consequently their perception of pain is relativised and downplayed. Bosphorus disease means that the patients' complaints are given a racially charged label, which is in clear continuity with colonial thought patterns. This pejorative term of Morbus Bosphorus is used as a supposed analysis which is usually based on biases of the treating forces from the global North.

## **2. What needs to change?**

A good and detailed medical history is necessary for the correct diagnosis and helpful in order to initiate the necessary therapeutic and medicinal measures promptly without wasting too much time. Language barriers therefore not only complicate the anamnesis, but also represent an obstacle to the decisive initiation of therapy. It is crucial for healthcare providers to ensure effective communication with patients from different linguistic and cultural backgrounds in order to address their health issues as accurately as possible. Furthermore, medical professionals should not have biases towards people

from the Global South by declaring these patient groups as "difficult cases" from the outset, based on their appearance, skin colour and origin, just because they cannot immediately express their physical complaints. This prejudiced attitude on the part of doctors can lead to broken trust on the part of the patient and should therefore be avoided at all costs. It is therefore important to learn antiracist concepts during preparatory seminars in secondment programmes and also to work on the (technical) language skills of the relevant regions.

BIPOC patients are afraid that their problems will not be recognised and, as a result, they do not feel taken seriously. They are constructed as "others" and made to "remain silent". The concept of "othering" from post-colonial theory describes a process of differentiation in which an imagined "us" is demarcated from the "others" and "strangers". The "we" is set as the norm and the "other" as a deviation, which leads to subjugation and marginalisation. In the medical care of patients in the Global South in particular, "othering" can intertwine various forms of discrimination. For example, doctors who received their training in the Global North only attribute certain symptoms/complaints to certain clinical pictures and use this "white norm" as a guideline for orientation. Due to this approach, BIPOC patients in the global South see themselves at a disadvantage in the context of medical secondment programmes. The consequence of this approach is that those affected are denied their symptoms and "silenced".

Studies by Johnson et al. (2004), M. A. Aikins et al. (2021) and Hamed et al. (2020) have shown how prejudices and distinctions between "us" and "them" lead to inequalities in healthcare. BIPOC patients are often constructed and viewed as "others", which leads to a constant belittling of and discrimination against them.

This contributes to the normalisation of racist behaviour among medical staff in the Global North. Those affected report a lack of respect and recognition as equal dialogue partners. Medical staff can cause delays in treatment due to their discriminatory behaviour. These discriminatory experiences can lead to serious psychological stress and a loss of trust in the care structures.

"Silencing leads racialised groups to reduce their communication and thus diversity in discourse as well as in the medical paroxysm. Silencing can be divided into two forms in the field of medicine. In "testimonial queiting", a person is not recognised as knowledgeable due to prejudices and stereotypes. In "testimonial smothering", on the other hand, BIPOC patients, for example, silence themselves due to the supposed ignorance of the other person by thinking back to past actions and remembering that their complaints were neither taken seriously nor listened to. In doing so, those affected shorten or simplify their speech. By not listening, an active practice of not knowing or not wanting to know is constructed, which is deeply rooted in colonial continuities. Both forms of silencing can be triggered by racist microaggressions, e.g. in medical contexts.

However, not all patients only have physical complaints. Somatic complaints can also have psychosomatic causes. Psychosomatics deals with the interaction between the mind (psyche) and the body (somatics). It examines the extent to which psychological factors such as emotions, thoughts, beliefs or stress can affect physical health. Psychosomatics allows conclusions to be drawn about physical complaints that are caused, intensified or maintained by psychological influences. This makes racism-sensitive, cultural competences of healthcare professionals to be deployed all the more important in order to ensure high-quality, patient-oriented healthcare in North-South contexts.

### **3. How can things change?**

Cultural competence is defined as "the ability of individuals and systems to respond respectfully and effectively to people of all cultures, classes, ethnic backgrounds, sexual orientations and beliefs or religions in a way that recognises, affirms and appreciates the value of individuals, families and communities and protects and preserves the dignity of each individual. Particularly when providing

healthcare to BIPOC patients in the Global South, it is necessary to adequately consider the needs and cultural backgrounds of these patient groups.

Sensitivity to discrimination and racism enables healthcare professionals to build trust with patients and thus ensure personalised treatment. Discrimination-critical and culturally sensitive care can help to reduce inequalities and ensure equitable healthcare for all population groups. It is therefore important to strengthen intercultural and anti-racist competences in order to meet the needs of BIPOC patients.

With regard to racist prejudice against certain patient groups, especially BIPOC in the Global South, important changes should be initiated in medicine that are necessary to ensure more equitable healthcare, especially in the Global South. It is crucial to raise awareness of the existence of structural and individual racism and colonial continuities in healthcare. Therefore, medical professionals from the Global North should continuously participate in education and training in intercultural and anti-racist competences in order to eliminate inequalities and injustices in the treatment of BIPOC patients in the Global South. It is important that medical staff in secondment programmes are made aware of racism (especially anti-black racism) in order to provide treatment that is critical of discrimination and racism.

Especially during their studies, medical students learn to think in categories and categories in order to quickly recognise the causes and symptoms of diseases and assign them to a clinical picture. This is exactly where prospective medical students should start when unlearning, so that they do not allow themselves to be guided by trained behaviours that refer to prejudices and stereotypes and consequently treat patients unequally on the basis of innate human differences such as skin colour, origin or gender.

In particular, efforts should be made to ensure that the diagnosis and treatment methods for BIPOC patients are adapted according to their needs. Care should also be taken to ensure that new findings in medical research are not exclusively focussed on white cis-male patients, but that the needs of different patient groups are also taken into account. One example of this is the pulse oximeter, which is used to measure oxygen saturation. This medical device can be used to determine whether the patient's blood is sufficiently saturated with oxygen. During the COVID-19 pandemic in particular, this device was increasingly used to diagnose dangerous readings as quickly as possible. Studies have shown that skin pigmentation (i.e. the more melanin the skin has) can influence the accuracy of pulse oximeters. Recent studies have found that this medical device systematically underdiagnoses Black people. The paper by Mona Abd Alla in the "Medicine for All?" project offers more in-depth insights into this.

It is important to understand the connections between physical and psychological factors in order to provide comprehensive treatment for patients. If patients from the global South, for example from the SWANA region, are cared for by doctors from the global North, there may be language barriers or insufficient intercultural and racism-critical competences, it takes time and resources to close these gaps. The problem analysis has clearly shown that their roots are structural, institutional and historical. Consequently, a lot of time is needed for structural and institutional change. At the same time, each individual can make a contribution, even if it is only through a lifelong unlearning of one's own biases or the critical questioning of informally used supposed diagnostic terms such as Morbus Bosphorus.

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