

## Spare a thought for patients with rare diseases

They are being undone by misdiagnosis, lack of awareness and treatment options

In a country where the vast majority of ordinary patients – those with easily diagnosable diseases – are often deprived of the care and treatment that they deserve, it's easy to overlook the small minority of patients afflicted with rare diseases. But their plight is no less dismal. As well as enduring problems that patients in general do in terms of access, cost and quality of care, those with rare diseases also suffer from misdiagnosis, lack of awareness on the part of doctors, limited treatment options, etc.

As a recent report by this daily shows, these factors, coupled with lack of policy response from the health authorities, make this group of patients suffer disproportionately. The report presents a number of cases to illustrate their vulnerability. There is the case of Iraboti Roy, 40, a patient of the rare Myasthenia Gravis disease, who died a day after a doctor used a sedative on her that allegedly caused the death; the case of Jakia Abedin, 36, another Myasthenia Gravis patient, who lost two babies just days after giving birth to them in 2006 and 2014; the case of Anisur Rahman, 9, suspected to be suffering from a premature ageing problem, the treatment of which is not available in his home district; the case of Sumona Monzur, also a Myasthenia Gravis patient, who had to wait for 12 painful years before her condition could be diagnosed.

Myasthenia Gravis – a chronic autoimmune, neuromuscular disease – is one of approximately 7,000 rare diseases said to have been discovered so far. These conditions affect the lives of around 300 million people worldwide, according to an estimate. Being rare, it's understandable that doctors may not always be aware of them, nor is medication to treat them widely available. Delayed diagnosis or misdiagnosis is another factor, which may lead to potentially dangerous wrong treatment.

Cases examined in our report have shown that patients with rare diseases mostly suffered because of lack of awareness and information. Most rare diseases take more time to be diagnosed and treated, at a comparatively high cost, of course. But delays in detection and treatment – in a country where out-of-pocket health expenditure is 68.5 percent of the total cost – only increase the costs further. This makes poor patients like Jakia and Anisur even more vulnerable among their peers. Unfortunately, the policy response to this threat remains woefully inadequate – with no separate fund for rare diseases, no policy guidelines, no research, no awareness drive for patients and doctors, no change in how medical students are taught to approach symptoms, etc.

This lack of response represents a lack of priority in our already stretched healthcare system. But those suffering from rare diseases deserve as much attention and care as ordinary patients. And the onus for that falls squarely on the health authorities, both at the policy level and at the medical college/hospital level. They must combine to form a national policy that addresses the threat of this growing challenge in the country.

## We must preserve historical records

National Archives authorities must do their job properly

We are disappointed to learn about the poor condition in which many historical documents are at the Bangladesh National Archives. While the state-run organisation is supposed to preserve our history through collecting and protecting records of historic value – newspapers, books, magazines, microfilm rolls, etc. – and to help researchers and readers to study and learn from them, it has been failing to live up to that mandate. According to a report by *Prothom Alo*, many of these documents are on the verge of destruction because they were not preserved properly, following the scientific method. Reportedly, the institution could not do anything significant in the last 50 years due to structural weaknesses, inefficiency and lack of manpower.

The National Archives, situated in the capital's Agargaon area, has many rare historical records, including a report prepared by the Famine Commission on the terrible famine of Bengal-Bihar-Odisha in 1896. A copy of the report that has been preserved there is no longer in a readable condition, with the papers breaking down in pieces with a slight touch. There are many other authentic documents of important historical events that have been kept there, such as the maps of the Battle of Plassey, records of the Agartala Conspiracy Case, etc. – but those are also in a vulnerable state. What is more frustrating is that there are hardly any important documents on our War of Liberation. Due to the weakness of the preservation system, much of the 90 million pages of documents that are kept there is being lost.

Why has the situation turn out like this? Do we not care about preserving our history, particularly the history of the Liberation War? If we do, why are there no important documents related to this? Why is the process of accessing existing documents so cumbersome? Reportedly, researchers cannot access multiple documents at one time, and the charge for copying the documents is also high. What is the point of keeping so many important national documents if they cannot be accessed by those needing them? Why are the documents – which are in a fragile condition – not being digitised? The National Archives authorities must answer these questions.

The Directorate of Archives and Libraries was established in 1972 under the leadership of Bangabandhu Sheikh Mujibur Rahman to preserve our national history, culture and heritage. And the Bangladesh National Archives Act 2021 was passed last year with the same goal. According to the Act, no historical record can be destroyed, and every record has to be archived.

If the way the National Archives authorities are doing their job currently does not change, the nation will soon lose many important historical documents that offer vital proof of events that define us as a nation. We cannot let that happen. We urge the authorities concerned to take proper steps to preserve whatever historic documents are left with them.

## An uncompassionate act on a compassionate ground

Why can't Bangladesh ditch the inhumane colonial practice of arbitrary fettering?



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The distressing image of Ali Azam, president of the Boali union unit of the BNP in Kaliakair upazila of Gazipur district, leading the funeral prayer of his mother in fetters and handcuffs has exposed the emptiness of so-called compassion in our policing and prison system. It is well known that parole is granted only on the ground of compassion to anyone under custody, irrespective of conviction or even if they are under trial. But Ali Azam's case has proven that such a compassionate act can also become egregiously uncompassionate behaviour.

Though this excruciating image has drawn widespread condemnation within the country, the government seems to be unmoved. Neither has any action been taken against those involved in such inhumane treatment of a detainee, nor has any investigation been ordered, despite a rare intervention by the National Human Rights Commission (NHRC) in this regard. The only voice heard was that of Information Minister Hasan Mahmud, who said that taking off Azam's fetters and handcuffs during the prayer would have been better. Lack of any administrative action against the officials involved indicates there was no contrition or remorse within the government over such degrading and cruel behaviour.

Press reports quoted Gazipur jail superintendent Mohammad Bazlur Rashid as saying that police acted as per the law. He said, "According to the Jail Code, any accused must be bound with handcuffs and fetters even if they are released for a while on parole." The code referred to by the jail superintendent is the Prisons Act, 1894, from which this degrading provision has long been stricken off in India and Pakistan, the two other parts of the then British India.

In India, the decision to bind an accused is no longer at the discretion of the prison authority or police, but of the judiciary instead. The Supreme



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Court of India, in its directives, made it a requirement for agencies of law enforcement to ask the court's permission before handcuffing a person.

In 1980, in *Prem Shankar Shukla vs Delhi Administration*, the court examined the rationale behind fetters and held that handcuffing is prima facie inhuman and hence unreasonable as well as arbitrary in the absence of fair procedure and objective monitoring. The court observed that when there is no compulsive need to fetter a person's limbs, it is sadistic, capricious, despotic, and demoralising to humble a man by manacling him. Thus, the Indian court concluded that handcuffs must be the last refuge and not a routine regimen. Furthermore, the court held that the escorting officer must show reasons to the presiding judge as to why the accused should be handcuffed and get the judge's approval before going through with the act.

A February 2022 report by *The*

SC considered a letter written by journalist Kuldeep Nayar recounting the ordeal of detainees under the Terrorist and Disruptive Activities (Prevention) Act (TADA) in Guwahati at a hospital, where they were handcuffed to their beds despite the room being barred and several policemen guarding the room. The court concluded by saying, "We declare, direct and lay down as a rule that handcuffs or other fetters shall not be forced on a prisoner – convicted or under-trial – while lodged in a jail anywhere in the country or while transporting or in transit from one jail to another or from jail to court and back."

In Pakistan, it happened a decade later.

The Pakistan Supreme Court, in 2006, barred police from putting fetters on prisoners in jails without seeking the approval of the district and sessions judges on the recommendation of the inspector-general of prisons. According to *Dawn* newspaper, a bench comprising Chief

Justice Iftikhar Muhammad Chaudhry and Justice Mohammad Nawaz Abbasi, in a suo moto notice following a complaint from a prisoner, also asked sessions judges that before granting such approvals, they should scrutinise whether the prisoner in question was involved in a heinous crime and could be termed a hardened criminal. The prisoner who had complained to the court had stated that he was put into fetters whenever he was taken for court proceedings, though the shackles were removed when he was confined inside the jail.

In Bangladesh, a High Court bench, in 2017, had issued an order restricting the use of bars and fetters only on court premises. It, too, was a suo moto directive, as four accused persons were produced before the bench in fetters. The court, however, did not ban its use altogether or during prisoners' transportation between prison and the courts.

The jail code cited by the Gazipur jail superintendent allows him and his superior authority, the Inspector General of Prisons, to consider whether it is necessary (with reference either to the state of the prison or the character of the prisoners) for the safe custody of any prisoners that they should be confined in irons. But the words "Prisoners under Sentence" in 57(l) of the Prisons Act, 1894, also suggests under-trial prisoners or suspects in custody should not be forced into fetters.

It has been reported by the media that, following the two condemned militants' escape from a crowded Dhaka court, police have resorted to using fetters to restrain dangerous criminals. Justifying the imposition of fetters on Ali Azam, police have argued that he's been implicated in a case involving explosives.

This argument raises another issue of the unethical but widespread practice of so-called *gayebi mamla* (fictitious or fabricated cases) filed by police or by coerced or misled complainants. Media reports have found that the person who filed the case against Ali Azam was kept in the dark about the complaint and knew no information about the alleged crime. We need to bring an end to all these practices.

If the rest of the sub-continent can ditch the inhumane colonial legacy discussed above, why can't Bangladesh?

## Without good teachers, any education reform agenda is futile



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One of the critical issues of education reform policy agendas is reducing graduate unemployment in Bangladesh. So far, numerous write-ups have been published through various outlets reflecting the state of unemployment, and expressing concerns about the existing education system. The central message is that our education system, for higher education in particular, fails to prepare graduates with the soft and hard skills necessary to make them employable. Moreover, in our society, it seems that becoming employed is the main purpose of acquiring an education.

In Bangladesh, many education reform initiatives are underway at various levels with this goal in sight. At the government level and in universities, the focus is on enhanced opportunities for technical and vocational education. Some exemplary initiatives include the founding of technical and vocational education centres across the country at the upazila levels, and the National University launching skills-focused diploma programmes.

It would not be an exaggeration to state that the main purpose of education should be to create an educated society and a civilised nation, rather than producing graduates for the job market. As for

higher education, the vision of an education institution should be to create knowledge, advance existing knowledge, and promote innovation.

But how can we reach a reality of all our graduates being employable in their respective fields, in Bangladesh or abroad?

On June 19, 1999, the Joint

exclusively on employability, though. But with the specific priorities in focus, the European countries reformed their education systems, curricula, and degrees, which ultimately resulted in increased opportunities of graduate employment thanks to increased inter-country mobility of graduates. As the quality of education was at par across the Bologna Declaration member countries, the graduates of one country did not experience difficulty finding employment in another country. In short, the reform initiative broadened the horizon of graduate employment opportunities.

During British rule, formal education was introduced in India to educate the citizens of this region, and higher education was established to create an elite class who would be

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Declaration of the European Ministers of Education (or, the Bologna Declaration) was signed. The education ministers of the 29 signatory European countries decided on the three priorities of higher education, with the main goal being the achievement of higher education equality across Europe. Another priority was fostering employability, that is, building the skills of a graduate to make them employable in their area of interest. They did not focus

educated as per Western standards of education and would serve the British rulers in delivering public service across India. After the end of the British rule, the British system of higher education was the norm, wherein access to higher education was extremely limited. However, the elite nature of higher education did not persevere.

Once Bangladesh gained independence in 1971, the country replicated the British system of

higher education but introduced higher education opportunities for the masses, and new colleges and universities were founded.

Consequently, the massification of higher education took place across the country that resulted in a huge supply of university graduates. The supply was much higher than what the job market demanded, though. And the inevitable outcome of the mismatch was a persistent rise of graduate unemployment. Despite having the required skills, many graduates were unable to get employment. And over the years, because of accumulated pressure, graduate unemployment has become one of our foremost economic problems.

The solution to this problem lies in generating more opportunities for the employment of our graduates – at home and abroad.

This is why an employment-focused reform initiative for education is erroneous. The reform agenda must cover raising the standard of education and improving the reputation of institutions, so that our graduates are universally fit for employment.

However, raising the quality of education does come at a cost. Sufficient investment is required for education at the government and private levels. And, of course, investment must be made in making the teaching profession attractive to the best and brightest graduates by enhancing the social status and financial packages associated with the post. Only higher spending by the government is unlikely to guarantee quality education. The secret to quality education for a nation is employing good teachers in the first place.