

IN THE HIGH COURT OF JUDICATURE AT PATNA
Civil Writ Jurisdiction Case No.10986 of 2021

1. Amit Kumar Agarwal, S/o Sri Mohan Lal Agarwal, Resident of 72, Kaveri Apartment, Bandar Bagicha, 9 to 9 Supermarket, New Dakbunglow, Phulwari, Patna, Bihar- 800001.
2. Sunil Sharma, S/o Sri Omprakash Sharma, Resident of Sher Singh, H.N.- 35, M.C. Colony, Tech Dadri, Dadri, Bhiwani, Haryana- 127306.
3. Mukesh Kumar Hissariya, S/o Ram Kumar Hissariya, Resident of 204, Aarya Appartment, Opposite Dr. RC Paul, Near Jahaji Kothi, Dariyapur Gola, Kadamkuan, Patna- 800003.

... .. Petitioner/s

Versus

1. The Union of India through the Secretary, Ministry of Health and Family Welfare, Room No. 348, A Wing Nirman Bhavan, New Delhi- 110011.
2. The State of Bihar through Principal Secretary, Department of Health and Family Welfare, Government of Bihar, Main Secretariat, Patna- 800001.
3. Additional Chief Secretary, Social Welfare Department, Government of Bihar, Main Secretariat, Patna- 800001.
4. Director, Directorate of Empowerment of persons with disabilities, Department of Social Welfare, Government of Bihar, Main Secretariat, Patna, Bihar- 800015.

... .. Respondent/s

Appearance :

For the Petitioner/s : Mr. Vishal Kumar Singh, Advocate
Mr. Deepak Kumar Singh, Advocate
Mr. Akash Keshav, Advocate
Ms. Akanksha Malviya, Advocate

For the Respondent/s : Dr. K. N. Singh (ASG)
Mr. Kumar Priya Ranjan, CGC
Mr. S.D. Yadav, AAG-9

CORAM: HONOURABLE THE CHIEF JUSTICE
and
HONOURABLE MR. JUSTICE P. B. BAJANTHRI
ORAL JUDGMENT

(Per: HONOURABLE THE CHIEF JUSTICE)

Date: 01-11-2021

Following issues arise for consideration in the
present petition:-

1. Is not the State under an obligation to make



available all facilities, including blood, to patients who have the disability of Thalassemia?

2. Is the refusal of blood on account of unavailability to patients suffering from Thalassemia a ground available to the State?
3. Is the State obligated to pay compensation to the families of the patients suffering from Thalassemia who died due to the non-availability of adequate medical facilities?

2. The petitioners in the present case are all individuals directly or indirectly affected by Thalassemia, and they are all committed to working to better the people suffering from this disease. Allegedly, in light of the COVID-19 pandemic and the condition of patients suffering from Thalassemia in the State of Bihar has become increasingly critical with an apparent rise in fatalities with each passing day. This can be attributed to a shortage of blood and a lack of arrangements for proper treatment. Numerous reports published in National Dailies and online portals have reported on the sad state of affairs.

3. The petitioners have cited seven real-life instances from where an apparent lack of proper medication and blood has resulted in five fatalities, namely Sonu Kumar (aged nine years), son of Vijendra Yadav, resident of village- Basvelli, P.O.



Tolli, P.S.-Dagrawa, District –Purnea, Bihar, Diwakar Kumar (aged 2.5 years) son of Sri Ajit Kumar, resident of Village-Kairin, P.O. Dulmanjhi, District-Purnea, Bihar; Shivam Kumar (aged five years) son of Sri Mantu Kumar Mandal, resident of village- Bhavanipur, P.O.-Dulmanjhi, District- Purnea, Bihar; Qumar Parveen (aged six years) son of Sri Shakir Alam, resident of Village- Bhokraha, P.O.-Dulmanjhi, District-Purnea, Bihar; and Sahil (aged three years) son of Sri Ibnul Haq, resident of Village-Amgachi, District-Purnea, Bihar, and the other two, namely Shubham (aged seven years) son of Sri Anil Kumar Sahani, resident of Muzaffarpur, Bihar and Md. Talha Tanveer (aged three years), son of Md. Tanveer Alam, residing at Muzaffarpur, Bihar, continue to suffer. One common contention of all was the lack of medical resources and other essential equipment for treating Thalassemia patients. Some patients and their relatives have further contended that blood is being sold on the black market. The petitioners contend that each of these instances brings forth a chilling realization for the need to introspect.

4. Thalassemia is an inherited blood disorder characterised by less Oxygen-carrying protein (haemoglobin) and fewer blood cells in the body than the normal. In brief,



Thalassemia is inherited from parents to children through genes. There would be blood disorder when the body does not make enough of a protein called haemoglobin, an important part of red blood cells. When there isn't enough haemoglobin, the body's red blood cells don't function properly and they last shorter periods of time, so there are fewer healthy red blood cells travelling in the bloodstream. Red blood cells carry oxygen to all the cells of the body. Oxygen is a sort of food that cells use to function. When there are not enough healthy red blood cells, there is also not enough oxygen delivered to rest of the cells of the body, which may cause a person to feel tired, weak or short of breath. This is a condition called anaemia. People with Thalassemia may have a mild or severe anaemia. Severe anaemia can damage organs and lead to death.

5. Prevention of Thalassemia would be very hard since the disease is passed from parents to children. Treatment consists of vitamins and transmission of blood in fact for the purpose of medication vitamin, blood transmission and iron reducer are required to be taken note of.

6. A significant equipment requirement for treating Thalassemia patients is filters used to ensure that the iron level in the bloodstream of patients does not increase beyond the



acceptable threshold. If so does, it may result in potentially fatal iron poisoning.

7. However, one issue that all patients face is the non-availability of filters in hospitals which is considered indispensable during the treatment of Thalassemia. In addition to the lack of filters in hospitals, there is also a dearth of medicines that are neither available in hospitals nor in medical stores and can only be acquired through Thalassemia Societies.

8. Further, Desferal, a drug that costs Rs.1500/- and its pump costs around Rs.33,000/- - Rs.35,000/- each, is considered the most essential component of Thalassemia treatment. However, none of them is available with hospitals and parents are expected to buy and provide the same to the hospital if they want their child to be treated.

9. As per reported statistics, 25% of all cases reported in India are from Bihar and Uttar Pradesh. As per the March of Dimes Global Report on Birth Defects, India has a prevalence of pathological hemoglobinopathies of 1.2 per 1000 live births. Further, treatment of Thalassemia was part of India 12th Five Year Plan (2012-17) and, in light of its incurable nature, was recognized as a disability under the Right of Persons with Disabilities Act, 2016.



10. The Petitioners have suggested to the Hon'ble Court that the State undertake the establishment of Thalassemia Day Care Centres (TDCC) to ensure that patients don't suffer the brunt of Iron overdose, which is one common side effect of Blood Transfusion. They have requested the Court to take the required steps.

11. The Government, through the counter affidavit filed by Respondent, has highlighted the action taken and further action proposed to be taken. It is submitted that the Health Department of the State of Bihar is actively pursuing the matter and enhancing infrastructure to deal with specific conditions of patients suffering from Thalassemia. Some of the initiatives which the Government has taken are as follows:-

1. Carrying out awareness, education and screening programmes in the community and schools
2. Establishing labs to carry on screening for hemoglobinopathies.
3. Screening Pregnant Women and their husbands to prevent the birth of children with Thalassemia.
4. Establishing prenatal diagnostic centres in medical colleges.

12. It is also submitted that the Government of Bihar has been very conscious of adhering to the Guidelines of the



National Health Mission. Moreover, the Government has stated that they are pursuing the establishment of Day Care Centres - 'Integrated Centre for Hemoglobinopathies and Haemophilia' in PMCH, Patna, SKMCH, Muzaffarpur, JNMCH, Bhagalpur, ANMCH, Gaya and Sadar Hospital, Purnea, on a priority basis. Of these, PMCH and SKMCH are already functional. These centres are fully dedicated to the treatment of Thalassemia, Haemophilia, and Sickle Cell Anaemia. The Day Care Centre at PMCH, Patna, is one of its kind and is fully functional to provide timely treatment to the patients with all the necessary facilities. For ensuring a consistent supply of blood for Thalassemia, storage centres have been established at the Day-care Centres where blood units will be stored after being collected from different blood banks. Additionally, a website, **thalassemiaregistry.bihar.gov.in** has been set up so that the patients suffering from this disease can self-register for appointments with doctors etc.

13. Moreover, the State has 38 districts, and Thalassemia treatment facilities and blood banks are available in all the districts except Sheohar and Supaul. The blood banks in all the districts are providing blood to Thalassemia patients as and when required. All 98 blood banks throughout Bihar (Page-15-



21) are providing blood to these patients where more than 984 patients are registered. In each one of these districts, regular meetings with the district level authorities are held to take stock of the situation to the districts and accordingly, directions for better implementation are given as and when required. In addition to all the steps mentioned above, the Government is vigilant about the issues with patients of Thalassemia and has installed modern and scientific equipment for the said purpose, and it also strives to take any other step which shall provide relief to those affected with Thalassemia.

International Obligations

14. The Constitution- its values, rights, duties, and responsibilities are the guiding light that we follow in any and all cases, but we must also pay heed to important international instruments that put a positive obligation on the State to ensure the Right to Health to its citizens.

15. Primarily, the Universal Declaration of Human Rights (1948) deals with the issue containing Article 25, which reads as under:

“Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to



security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.”

16. International Covenant on Economic Social and Cultural Rights, (1966) which India acceded to in 1979, states-

“Article 12

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

(a) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;

(b) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.”

17. UN Convention on Rights of Persons with Disability which India ratified in 2007, contains articles that reads as under:

“Article 5 :

2. State Parties shall prohibit all discrimination on the



basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

3. In order to promote equality and eliminate discrimination, State Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.”

“Article 25- Health

“States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities,



including among children and older persons;

- c) Provide these health services as close as possible to people's own communities, including in rural areas;
- d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- f.) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.”

World Health Organization Constitution (1946)

18. Preamble to the WHO Constitution reads as under:

“The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.”

19. In light of India's commitments, having ratified the United Nations Convention of Rights of Persons with Disability, the Apex Court in **Vikash Kumar v. Union Public Service Commission, (2021) 5 SCC 370**, speaking via Dr. Justice D.Y



Chandrachud, elaborating upon the concept of “reasonable accommodation” and the Rights of Persons with Disabilities Act, 2016, stated: “Intrinsic to its realization is recognizing the worth of every person as an equal member of society. Respect for the dignity of others and fostering conditions in which every individual can evolve according to their capacities are key elements of a legal order which protects respects and facilitates individual autonomy... The law does this by imposing a positive obligation on the State to secure the realization of rights. It does so by mandating that the State must create conditions in which the barriers posed by disability can be overcome. The creation of an appropriate environment in which the disabled can pursue the full range of entitlements which are encompassed within human liberty is enforceable at law.”

20. Profoundly, they state further ahead- “The principle contains an aspiration to meet the needs of the class of persons facing a particular disability. Going beyond the needs of the class, the specific requirement of individuals who belong to the class must also be accommodated.”

Right to Health under the Constitution.

21. As this court has held, keeping in mind the values that



define the core of justice within a democracy in **Ankit Abhishek v. State of Bihar** (LPA 255 of 2020) (reproduced from a judgment of the Hon'ble Supreme Court in **Consumer Education & Research Centre and others Versus Union of India & Ors. (1995) 3 SCC 42:-**

“The concept “social justice”, which the Constitution of India engrafted, consists of diverse principles essential for the orderly growth and development of personality of every citizen. “Social justice” is thus an integral part of ‘justice’ in the generic sense. Justice is the genus, of which social justice is one of its species. Social justice is a dynamic device to mitigate the sufferings of the poor, weak, dalits, tribals and deprived sections of the society and to elevate them to the level of equality to live a life with dignity of person. Social justice is not a simple or single idea of a society but is an essential part of complex social change to relieve the poor etc. from handicaps, penury to ward off distress and to make their life liveable, for greater good of the society at large...of a society but is an essential part of complex social change to relieve the poor etc. from handicaps, penury to ward off distress and to make their life liveable, for greater good of the society at large.”

22. An important aspect of striving to achieve social justice is to ensure the realization of the Right to Health for all citizens, in recognition of it being a part of the Right to Life under Article 21 of the Constitution of India. Also, by virtue of



Article 47 of the Constitution of India, the State is under an obligation to ensure raising the standard of public health. [(Paschim Banga Khet Mazdoor Samity v. State of West Bengal, (1996) 4 SCC 37; State of Punjab v. Mohinder Singh Chawla, (1997) 2 SCC 83; Union of India v. Moolchand Kharaiti Ram Trust, (2018) 8 SCC 32)]

23. Health enables a person to live their life with dignity. If treatment is scarcely available or, in an even worse scenario, denied, it puts the patient of Thalassemia squarely in the path of danger to their life, infringing their dignity.

24. The Hon'ble Supreme Court has said, quite profoundly in **National Legal Services Authority v. Union of India and Ors., (2014) 5 SCC 438**, that there is a growing recognition that the true measure of the development of a nation is not economic growth; it is human dignity. We must stand true to this vision of development.

The Right to Persons with Disabilities Act, 2016.

25. Thalassemia is mentioned under the head of blood disorders under this Act, and there are various responsibilities for persons with such disability that the State is duty-bound to fulfil.

“25. Healthcare. — (1) The appropriate Government and the local authorities shall take necessary



measures for the persons with disabilities to provide, —

- (a) free healthcare in the vicinity especially in rural area subject to such family income as may be notified;
 - (b) barrier-free access in all parts of Government and private hospitals and other healthcare institutions and centres;
 - (c) priority in attendance and treatment.
- (2) The appropriate Government and the local authorities shall take measures and make schemes or programmes to promote health care and prevent the occurrence of disabilities and for the said purpose shall—
- (a) undertake or cause to be undertaken surveys, investigations and research concerning the cause of occurrence of disabilities;
 - (b) promote various methods for preventing disabilities;
 - (c) screen all the children at least once in a year for the purpose of identifying “at-risk” cases;
 - (d) provide facilities for training to the staff at the primary health centres;
 - (e) sponsor or cause to be sponsored awareness campaigns and disseminate or cause to be disseminated information for general hygiene, health and sanitation;
 - (f) take measures for prenatal, perinatal and post-natal care of mother and child;
 - (g) educate the public through the pre-schools, schools, primary health centres, village level workers and Anganwadi workers;
 - (h) create awareness amongst the masses through television, radio and other mass media on the causes of disabilities and the preventive measures to be adopted;
 - (i) healthcare during the time of natural disasters and other situations of risk;
 - (j) essential medical facilities for life saving emergency treatment and procedures; and
 - (k) sexual and reproductive healthcare especially for women with disability.”



26. It is, therefore, the considered opinion of this Court, that Hon'ble the Supreme Court is absolutely clear in its holding of the Right to Health as a fundamental right, and also the broad and expansive nature of "reasonable accommodation." Within such reasonable accommodation for a particular class of people suffering from a specific disease, that is in the present petition, Thalassemia, would be all possible medication, facilities and care that may be required for those suffering from this blood disorder to realize their Right to Life and Liberty under Article 21 of the Constitution and the letter and spirit of the above stated UN Convention. In such a situation, unavailability or shortage of blood, medicines or any other essentialities needed for the treatment of Thalassemia patients is not a pathway available to the Government. The death of even a single person suffering from disability for lack of resources is an affront to the commitments of the State to international law and the values enshrined in the Constitution, and so, it is reprehensible that five children, namely Sonu Kumar, (aged nine years); Diwakar Kumar (aged 2.5 years); Shivam Kumar (aged five years); Qumar Parveen (aged six years); and Sahil (aged three years), have passed on. Though State has taken considerable measures in providing information and facilities to persons who have such



disability, however, what shocks the Court is conspicuous silence on the deaths of these innocent, helpless children, not even so much as an acknowledgement of this tragic situation is found in their averments to the Court. It, i.e. ensuring the right to health of its citizens, is one of the most important responsibilities of the country under a welfare State, of which an apparent failure is visible. The State is under an obligation to make available all facilities, including blood, to patients suffering from the disability of Thalassemia. Non-refusal of blood to such patients is not a ground available to the State. Equally, the State is under an obligation to compensate the family who died solely on account of non-availability of adequate medical facilities.

27. We are, therefore, constrained to direct the formation of an independent committee of doctors to take a survey of all the facilities present in the State, examine their readiness, availability, accessibility and quality, and submit a report on the same to the Chief Secretary, Government of Bihar within four months for taking appropriate action at all levels. The State additionally is to take all conceivable steps to ensure that such misfortunes do not befall any child in the future.

28. DIRECTIONS



(i) A committee comprising (i) Dr Chandra Mohan Kumar, Additional Professor, Paediatrics, AIIMS, Patna, cmkumar@aiimspatna.org (ii) Dr Ravikirti, Additional Professor, General Medicine, AIIMS, Patna, dr Ravikirti@aiimspatna.org (iii) Dr Avinash Kumar Singh, Consultant Haematologist, Paras HMRI, Patna, (iv) Dr Bankim Das, Assistant Professor in Transfusion Medicine, AIIMS, Patna, drbankimd@aiimspatna.org, is constituted with a two-fold mandate- (a) They shall inspect all the Institutions offering treatment to patients suffering from Thalassemia for examining their readiness, availability, accessibility and quality. (b) They shall also suggest suitable compensation for the five above named juvenile fatalities as reported by the petitioners.

The report so prepared within four months to be submitted to Chief Secretary, Government of Bihar.

- (ii) The State is to extend all necessary help to this independent committee in the formation of this comprehensive report.
- (iii) The Chief Secretary, Government of Bihar, upon receipt of such report to take action. He will also take appropriate action concerning the compensation



recommended by the Committee formed.

- (iv) The State must take all possible efforts to ensure that health-related needs, most importantly, as well as others, are met for those suffering from Thalassemia, and for vulnerable groups as a whole.
- (v) For the two cases, namely Shubham (aged seven years) and Md. Talha Tanveer (aged three years) highlighted by petitioners, the Government is to appoint an officer to verify the details and provide all the assistance permissible under the law to ensure that the number of fatalities is not increased beyond what has already occurred.
- (vi) Government to explore the possibilities of appointing a nodal officer per district who shall be responsible for ensuring that needs of people belonging to vulnerable groups have their needs met, and take appropriate steps in that regard.
- (vii) Blood banks should be set up at the earliest in the two districts, i.e. Sheohar and Supaul, in which they are absent, and constructive steps should be taken to ensure the proper availability of blood throughout the State.
- (viii) The State to ensure that the second child of Shri Vijendra Yadav, as mentioned in paragraph 14(a) of the petition, is given proper care entitled to as per the authorities mentioned above in this order.
- (ix) Liberty reserved to the petitioners to move an



application afresh if the need so arises subsequently.

29. We place on record our appreciation for the assistance rendered to the Court by various counsel engaged in this matter.

30. This writ petition and any associated interlocutory applications stand disposed of in the above terms.

(Sanjay Karol, CJ)

(P. B. Bajanthri, J)

K.C.Jha/-

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