

Thalassaemia, still a neglected disease

PROF WAQAR A KHAN

Thalassaemia is the most common congenital disorder in the world including Bangladesh, but one of the least known diseases among the people. Parents who carry the abnormal genes pass it to their children. A carrier is normally healthy and does not know his/her genetic haemoglobin status. The couple only comes to know when a child is born with thalassaemia and diagnosed a few months later resulting in a pathetic condition to know that there child will have to be given blood throughout his/her life along with chelating drugs due to accumulation of iron in the body. There is a 25% chance of a child suffering from thalassaemia if the parents are carriers.

The carrier status of thalassaemia trait is about 10% in Bangladesh which means that there are about 16 million carriers, but presumably less than 1% of the population is aware of it. More than 7,000 thalassaemic children are born each year although this may not be an accurate estimation as there is a wide variation in carrier status in different regions of Bangladesh with very high frequency in tribal people.



In thalassaemia, there is a defect in the production of haemoglobin leading to anaemia. In order to correct the anaemia, regular blood transfusion is needed. Regular blood transfusion results in excessive collection of iron in the body which is toxic causing damage to the heart, liver, pancreas and pituitary gland leading to organ failure. This iron needs to be removed by drugs which are expensive. The treatment is life-long. Bone marrow transplantation is the only cure but very costly and has many complications. Infant mortality rate is rapidly

decreasing in our country due to targeted vaccination programmes, better health care and nutrition with the rise of per capita income resulting in more children attending hospital with genetic disorders like thalassaemia. Thalassaemia poses demanding challenge in terms of managing with limited resources in developing countries like Bangladesh. Awareness, screening of carriers and prevention of births of thalassaemic children by prenatal diagnosis of couples is important. The role of gynaecologists and obstetricians is also important as

they should advise couples early to know their carrier status. In early 1970, Cyprus having one of the highest rates of carriers, started the programme of awareness and screening, but it failed to reduce the births of thalassaemic children as there were no facilities for prenatal diagnosis. But with the availability of facilities of prenatal diagnosis, the births of thalassaemic children has drastically fallen nearly to zero. Several countries like France, Hong Kong, Iran, Singapore, Thailand and United Kingdom have started comprehensive national preven-

tion programmes which include education, screening of carriers, counseling as well as information on prenatal diagnosis. Genetic disorders have been included in the 12th Five Year Plan in India and the country is now taking steps to prevent and manage hereditary blood disorders. In Sri Lanka the ministry is working to impose new laws to make premarital blood testing compulsory. In Bangladesh, every couple should be advised to have their carrier status known before marriage or in the early pregnancy and if anyone of the couple is positive for thalassaemia, DNA analysis should be advised with the option of abortion to the parents. DNA laboratories should be set up in every division with appropriate training facilities. The government should also create programmes to create awareness of the disease and screening a larger population. Recently the government of Bangladesh has started screening programme in a limited scale which is very encouraging and soon we want to see the births of thalassaemic children to drop rapidly like the rest of the world.

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Ending premature child deaths

A full-term pregnancy lasts between 37 and 42 weeks, and "prematurity" describes when a baby is born earlier than 37 weeks. Prematurely born babies face many problems, which can include breathing difficulties, feeding difficulties, and low birth weight.

The World Prematurity Day (WPD) was on November 17, 2016. Globally WPD observation started in 2011. The day is a key opportunity to generate attention onto the leading cause of deaths of children under 5 — complications from pre-term birth accounted for more than 1 million child deaths in 2016.

In Bangladesh, estimated 438,600 premature babies are born each year and this year estimated 23,600 will die. Bangladesh remains one of the top ten countries in the world with the largest number of premature deaths. Prematurely born babies generally need special care in hospital but unfortunately most of them in Bangladesh are born at home. Without a major push to reduce these deaths, it will not be possible to reach the Global Goal (SDG 3) endorsed by 194 countries including Bangladesh, to end all preventable newborn and child deaths by 2030.

While World Prematurity Day is an opportunity to call attention to the heavy burden of death and disability and the pain and suffering that pre-term birth causes, it is also a chance to talk about solutions. Bangladesh has made some major decisions in preventing the problem. Policy endorsement and incorporation in the Promise Renewed declaration was a key intervention for Ending Preventable Child Death by Ministry of Health in 2013.

Technical subgroup on Kangaroo Mother Care (KMC) formed by National Technical Working Committee on Newborn Health developed the national KMC guideline, training module, job-aids and monitoring including Health Management

HEALTH bulletin



Global progress on reducing child deaths

Estimates for 2015 suggest that 5.9 million children worldwide died before reaching the age of five, including 2.7 million newborns. Globally, 4.02 million fewer child deaths occurred in 2015 than in 2000, mainly thanks to reductions in deaths from pneumonia, diarrhoea, death during birth, malaria and measles.

However, progress on reducing newborn deaths (in the first 28 days) has been slower meaning that as a whole the world failed to reach the Millennium Development Goal (MDG) target of reducing child deaths by two-thirds between 1990 and 2015.

The study, published in The Lancet, provides the most up-to-date figures for deaths of children under five years old and includes data for all 194 countries that are World Health Organisation states.

Although the number of newborn deaths was reduced from 3.9 million in 2000 to 2.7 million in 2015, progress has been slower than the improvements in survival for one month to five year olds.

If newborn deaths had reduced at the same rate as that of children aged between one month and five years old the MDG target to reduce child deaths by two-thirds between 1990 to 2015 might have been reached.

Respiratory Distress Syndrome: A major threat to newborn babies

DR RICHARD HUBBARD

The birth of a new baby is a joyous time for most of the families. For those born prematurely, however, this period can be very dangerous. Premature babies do not have fully formed lungs, and they are at risk of developing a breathing disease called Respiratory Distress Syndrome (RDS). Without proper care, about half of all babies with RDS will die. This disease is one of the leading causes of death for newborns worldwide.

New research is shedding light on this problem in Bangladesh. Dr Kamal Choudhury, Head of Paediatric Surgery at the Bangladesh Institute of Research and Rehabilitation in Diabetes, Endocrine and Metabolic Disorders (BIRDEM) Hospital, and Dr Richard Hubbard, a physician at The University of Pittsburgh in the USA, have lead a team of researchers in analysing the risks of death from RDS.

Despite some modern facilities such as ventilation equipment, death rates remain high at 36%. In hospitals with fewer facilities, specially in the rural areas, the death rate is likely much higher. The sad truth is that many thousands of



babies in Bangladesh are at risk of dying each year from this disease. Bangladesh has made wonderful progress towards improving childhood mortality in the last several decades, largely through successful vaccination and primary care efforts.

In order to make further advancements, resources must be allocated to improve neonatal care, specifically in making ventilation equipment and medications more univer-

sally available throughout the country. Fortunately, low-cost alternatives, such as the Pumani CPAP machine, mean that these technologies need not to be overly expensive.

There is hope to improve the state of Bangladesh's newborn babies. We need only to make the commitment.

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BSCF held dialogue on breast cancer

STAR HEALTH REPORT

The Blue Sky Charitable Foundation (BSCF) recently held a dialogue with the physicians and breast cancer patients at the Dhaka Medical College Hospital (DMCH) outdoor premises, says a press release.

BSCF also organised a health camp team in association with Doctors' Care General Hospital in Brahmanbaria district to raise awareness about breast cancer and its prevention, detection, consultation and treatment in a meeting held earlier this month.

Founder of Doctors' Care General Hospital Dr Rahima Khatun gave her speech in the meeting. Dr Rezina Khatun, Ms Rubana Kafi Jharna and Md Rashedul Murad were present on behalf of the foundation.

Some breast cancer patients were provided treatment and financial aid later on this occasion.

  /StarHealthBD



World Antibiotic Awareness Week aims to increase awareness of global antibiotic resistance and to encourage best practices among the general public, health workers and policy makers to avoid the further emergence and spread of antibiotic resistance.

The theme of the campaign, Antibiotics: Handle with Care, reflects the overarching message that antibiotics are a precious resource and should be preserved. They should be used to treat bacterial infections, only when prescribed by a certified human or animal health professional. Antibiotics should never be shared or saved for the future.

