DOI: https://doi.org/10.47391/JPMA.669

Neural tube defects, their implications and solutions in Muslim society

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Abstract

Neural Tube Defects (NTDs) are serious congenital abnormalities and most of them are incompatible with life. The extremely debilitating quality of life, if one survives, calls for actions to prevent such sufferings. Experts agree on the role of Folic Acid in primary prevention of NTDs, yet, despite best efforts, the use of Folic Acid has reduced NTDs by only 50%. These cases too can be prevented by employing secondary preventive measures. These involve timely interruption of pregnancy -- a decision which, in addition to a medical judgment, is based on ethics, social, cultural and Muslim religious value systems in Pakistan. Indeed, it is a complex issue but empathic understanding and strong co-ordination, once established between different disciplines, can help parents to decide and opt for necessary secondary prevention by interruption of malformed foetus within the given time frame mandated by medical and religious authorities.

Keywords: Neural Tube Defects, Interruption of Pregnancy, Pakistan, Ethics, Muslim

Case Vignette

Ahmed (name changed), a three-month-old make baby (5kg) had Lumbosacral Meningomyelocele (MMC) and Hydrocephalus – Neural Tube Defects – since birth and was being treated at Combined Military Hospital (CMH) Peshawar. He was operated on by the neurosurgical team in October 2018. Within one week of surgery, the baby developed the common complication of 'shunt blockade' as well as Aspiration Pneumonia. He was admitted to paediatric intensive care unit (PICU) and later on shifted to Military Hospital (MH) Rawalpindi for further expert management. Because of the unstable clinical condition, he could not be operated upon immediately for shunt blockade and so supportive care was provided at the MH Rawalpindi. Meanwhile, the baby developed stridor (noisy breathing) due to raised intra-cranial pressure (ICP).

As stridor was due to the pressure effects, it was decided to do ventricular-tap on daily basis in order to reduce the pressure effects. After a week of daily ventricular-tap of approximately 40-50ml, there was a dramatic improvement in his stridor and within a few days it disappeared completely. Neurosurgical opinion was obtained again for shunt blockade, and surgery was performed to resolve that. Subsequently, the baby stabilised clinically, started tolerating oral feeds and was discharged after prolonged and painful processes of different treatments with an advice for regular follow-ups.

During this ordeal, the family was divided between decision to keep the baby at hospital or home consistently for many months, which led to improper care and illnesses in other children as well. But this may not be the end of trouble, because such babies frequently struggle with bladder/bowel problems, kidney issues and seizures, etc.

Case Report

The case vignette mentions a baby with Meningomyelocele (MMC) and Hydrocephalus, which are extremely serious birth defects in new borns.

According to a 2018 WHO report , every year 300,000 infants are born in Pakistan with severe birth defects and die within four weeks.[1] MMC, anencephaly and some other congenital anomalies are birth defects arising from inadequate development of neural tube and are grouped as Neural Tube Defects (NTDs). NTDs are second commonest birth defects. In Pakistan, the incidence of NTDs is 13.90 per 1,000 deliveries, while hydrocephalus, anencephaly and meningomyelocele are the commonest NTDs.[2]

In fact, NTDs are neural tube closure problems that occur at the very beginning of gestation (25-35 days). They often lead to lifelong disabilities because of sensory, motor, orthopaedic and urologic problems in the life to come. Parents of such children feel emotionally drained and develop anxiety, depression and other psychological problem[4] as satisfactory cure and treatment of severe forms of NTDs is still unavailable.

As mentioned above, on the one hand, the postnatal management of such defects doesn't provide satisfactory cure, and the infant and family have to bear the burden of disabilities for life in terms of emotional and financial baggage. And on the other hand, persistent care and hospitalisations put a lot of strain on hospital resources and skilled manpower with poor outcomes. The agony and frustration with which the family and infant goes through, becomes unbearable as time passes. These all have led to thinking-over about different strategies to prevent such congenital defects which are either incompatible with life or have extremely debilitating life conditions.

Promisingly, different technological developments in the field of medical diagnostics, in previous decades, have given us a window of handling them prenatally. NTDs can be diagnosed accurately, to a varying degree, with the help of screening maternal serum Alpha Fetoprotein (AFP) and subsequently, targeted and detailed ultrasound scan[5] in early second trimester -- solidifying the diagnostic accuracy. These results can be helpful in managing the pregnancy timely, if it turns out to have a problematic foetus, as done in many countries.

But, before that, is there anything which can be done to prevent NTDs occurrence in the first place? The answer is yes.

Discussion

The best strategy is always preventing a disease before it even occurs. In 1991, a MRC vitamin trial conducted in seven countries led to a remarkable revelation: Folic Acid can prevent NTDs in high risk women, if introduced well before conception[6] It is even beneficial for all women of reproductive age group. This led to a widespread Folic Acid use advisory by US public health service to all women of child-bearing age in 1992. It also led the world to fortify grains with Folic acid, and FDA even mandated that in 1998. In 2007, a follow-up trial by De Wals et al jotted down only 46% reduction in NTDs after all such measures even in a well-resourced environment of Canada.[7] Implicitly, it shows >50% cases of NTDs still occurred though Canada doesn't receive the greatest of NTDs burden as compared to poor places in the world, as shown by Yang J et al. in 2007[8] and Grewal J et al in 2008.[9] Countries such as Pakistan, where food fortification with Folic Acid is not mandated, literacy is low and most pregnancies are unplanned, have higher number of cases of NTDs, and far greater sufferings and non-optimal health resource utilisation. So, despite wonderful effects of Folic Acid, the prevailing situation asks for some other preventive measures at secondary levels as well, when NTDs do occur.

It has been revealed that if we can accurately diagnose a life-incompatible congenital anomaly at an appropriate time, then families can be helped in deciding about the interruption of such pregnancies. This secondary preventive strategy has been working well in many countries[4] having favourable laws, socio-cultural or religious value systems. In Pakistan, it is not working well and there are three reasons for this:

1. The inaccessibility of maternal serum AFP levels as a part of routine antenatal care early in the second trimester, which is a standard of care in US since 1980.[10]
2. Though detailed ultrasound scan (Anomaly Scan) is standard of care in most centres in Pakistan, there are inadvertent delays and expert ultrasonologists are not available in most mother and child health centres to accurately identify such defects.
3. If a case of NTD finally gets identified, despite above mentioned difficulties, there is a need to take the most important decision about interruption of pregnancy, which is not purely a technical decision but holds religious and ethical connotations. Pakistan, a predominantly Muslim society, needs an Islamic ruling on the subject, but there is no monolithic Islamic jurisprudence available. At the most, a range of rulings and opinions based on various schools of thought, are available which discuss ensoulment of foetus. Summarily, an overview of them, largely a resolution (fatwa) of The Islamic Jurisprudence Council of Makkah during its 12th session in February 1990, suggests that 120 days (19.14 weeks) in pregnancy is the maximum limit for interruption in case of foetal issues under a decision of committee of competent physicians.[3] Additionally, no ruling currently exists in Islamic jurisprudence which allows interruption of pregnancy based on foetal complications and anomalies beyond 120 days. Although, if the mother has serious issues which, in medical judgment, can be dangerous to her life; all muslim schools of thought accepts it for interruption of pregnancy even after 120 days.[4]

So, it's an extremely delicate affair. In a nutshell, screening facility of maternal serum AFP as well as expert ultrasonography should be available prior to 19.1 weeks of pregnancy, in order to proceed with the decision of interruption to avoid lapses on religious grounds. This extremely narrow window, where a huge difference can be made, calls for clear understanding of the issue by obstetricians, neonatologists, radiologists, pathologists, hospital administrators and health

policy makers. In our view, obstetricians, being the custodian of antenatal care, are the key players. They have to assume the lead role and essentially push hospital policy-makers for maternal serum AFP as standard of care in 15-16 weeks and detailed anomaly scans in 17-18 weeks of gestation.[11] Holding of sensitisation programmes from time to time by hospitals for all the above-mentioned specialists, can help obstetricians to make necessary co-ordination smoothly. It is also important to add here that all the strategies mentioned above can only work when patients report early for booking in case of pregnancy, so that obstetricians can plan their antenatal care in a standardised manner.

Additionally, religious scholars in general and Council of Islamic Ideology in particular are needed to deliberate on the issue of public importance. They need to consider the legitimate problem of foetus, which medical science is able to diagnose now, as a case of interruption of pregnancy after the 120-day period. After all, human sufferings and hardships have been considered as a valid reason to re-consider many of rulings for different situations including Haj. When abortion (medical interruption) is not absolutely immoral, then, carrying a known malformed foetus to term and push the women for it is an immoral act. It would also be unethical to knowingly act in a way which increases the suffering for life and bleed the scarce resources as well.

Conclusion

Neural Tube Defects are serious congenital anomalies where prevention is the best strategy. Medicine, religion and ethics needs to be on one page to solve this problem of humanity. The ideal is Folic Acid food fortification to maximise their primary prevention. Still, a lot of cases do occur and need secondary prevention. All stakeholders need to be educated and sensitised. Maternal serum AFP should be made part of routine antenatal care while Anomaly scans should be pushed-up in second trimester so that in case of NTD, if decided by parents, medical interruption of pregnancy can be done before 19.1 weeks. Religious scholars are

also urged to deliberate on such situations and pave the way for certain changes in rulings regarding interruption of pregnancy so as to lessen human suffering.

Note: 120 days (17.14 days) in Islamic fatwas are counted from the day of conception but in modern clinical practice Expected date of delivery (EDD) is calculated 2 weeks (14 days) prior to conception, which mandates to add 14 days or 2 weeks in 120 days, as mentioned in fatwas, for clinical considerations.

Disclaimer: Permission was sought from parents of baby to use the clinical data without identifiers and they happily consented.

Conflict of Interest: None.

Source of Funding: None.

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