Need for National Fetal Screening Programme for Congenital Anomalies

Sir,

Diseases like meningomyelocele, posterior urethral valves (PUV), and bladder exstrophy have tremendous impact on the quality of life of the baby. They also pose high financial burden and mental stress to the afflicted families. Meningomyelocele babies suffer from lifelong paralysis, incontinence etc, whereas babies with PUV and other congenital uropathies treated approximately account for upto 30% of the children requiring renal replacement therapy.¹ Exstrophy patients need several surgeries to achieve dryness and this disrupts normal childhood. The first author has treated over 285 PUVs, 49 exstrophies and has over 100 babies with neurogenic bladder (post myelomeningocele repair) on a regular follow-up in the last 15 years. With lack of state/governmental support and lack of health Insurance for the families, the cost of medical care of these babies is anywhere between 1 lac to 10 lacs through childhood depending upon the severity.

Fetal screening for congenital anomalies is part of the comprehensive health care of pregnant women in the overwhelming majority of the developed countries. Centers in developed societies have favored termination to fetal intervention in these diseases because of poor long-term postnatal outcome. The diagnostic sensitivity of antenatal ultrasonography at 17-20 wk of pregnancy for fetal anomalies was found to be very high in the United Kingdom. In a prospective study, in the Yorkshire region during 3 ½ year period 2261 anomalies were identified on ultrasound of which 369 (16%) prompted termination of pregnancy.² CNS malformation accounted for almost 50% of the terminations whereas genitourinary tract anomalies accounted for 9.5% of the terminations. No false positive results were identified. In several, studies a significant number of babies who underwent fetal intervention for posterior urethral valves and other fetal obstructive uropathies ended up with end stage renal disease at an early age in addition to complications like premature labour, fetal death etc.³ Several studies and fetal registries have confirmed that detection of dilatation of urinary tract in PUV before 24

wk is a poor prognostic factor and termination should be recommended. Termination of pregnancy of these fetuses has resulted in a tremendous impact in the postnatal incidence of these diseases.⁴ In a study, parents of 65% of the fetuses with meningomyelocele, 46% of the fetuses with PUV and 25% of the bladder exstrophy opted for elective termination. With the rapid decline of the incidence of these diseases, several countries have identified specialist centers to manage these problems. This also has reduced the social and financial burden of care of these babies.

Routine fetal screening for congenital anomalies must be followed in India as a National programme in order to achieve these social goals. The government must invest in the manpower and infrastructure to achieve this as it is cost effective and ethical. It should be left to the families whether they opt for termination after proper counseling. This facility must be available in all the districts and medical colleges and an attempt be made to cover all pregnancies.

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REFERENCES

1. Dharamsi N, Sheldon C, Goebel J. Renal transplantation. In Docimo SG. eds. *The Kelalis-King-Belman Text book of Clinical Pediatric Urology*. 5th ed, Informa Health Care UK, 2007: 367-385.
2. Brand IR, Kaminopetros P, Care M, Irving CH, Lilford RJ. Specificity of antenatal ultrasound in Yorkshire region: "a prospective study of 2261 ultrasound detected anomalies. *Br J Obstet Gynaecol* 1994;101:392-397.
3. Freedom AL, Johnson MP, Smith *et al*. Longterm outcome in children after antenatal intervention for obstructive uropathies. *Lancet* 1999;354:374-377.
4. Cromie WJ, Lee K, Honde K, Holmes L. Implications of prenatal ultrasound screening in the incidence of major genitourinary malformations. *J Urol* 2001;165:1677-1680.