Letter from Chennai

UNINFORMED NON-CONSENT

I wish to raise a controversy. A few days ago, *The Hindu* published a report of a female with lupus who had been unable to conceive for several years. She finally got pregnant, and was put on prednisolone, but despite this, the report said, the child was born at 27 weeks and weighed 1 kg. The child had congenital heart block. There have been only three reported cases of a pacemaker having been implanted in a 1 kg infant, and the paediatric cardiologist involved implanted the fourth. As the chest cavity was too small to accommodate the pacemaker, it was placed in the abdomen. The child did well and despite needing ventilator support for 70 days grew to 2.5 kg and was taking oral feeds at the time of discharge.

This is a remarkable feat, and not just the team involved, but all of us can be proud that we have the technical expertise to pull it off and send the baby home well. I am sure any reputed medical journal would readily publish a report of something that has been done only thrice before in the whole world. My first question is: why then go to a newspaper? The report carried the names of the hospital and all the doctors concerned. Is this not advertising? We do not have a genuine functioning regulatory body, and such reports are common enough though they should not be permitted, so I will not dwell further on this.

Lupus is a bad disease, and pregnancy is bad for lupus. There are numerous published reports in the literature with varying figures of the problems that could arise, but around 25% of females could have a lupus flare. Pre-eclampsia is more common, and there could be more serious complications such as the HELLP (haemolysis, elevated liver enzymes, low platelet count) syndrome. About 1% of females could die.

It is now widely accepted that people should be given all the facts and left to make the decision themselves. That is informed consent, and we are told that is the way to go. If you tell someone that there is a 25% chance of her getting into trouble, she will tend to think of the 75% chance that she will not, and would prefer to take it. Most Indians seem to believe that their prime duty in life is to produce more Indians, and they will always opt for the chance to do so. I have no doubt the doctors would have given this female all the facts and figures, and would have spelt out all the possibilities, and when she still chose to try, they gave her all the support that modern medicine can provide. So where is the controversy that I threatened to raise?

About 60% of human nephrons develop in the third trimester of pregnancy, and nephron numbers are low for any child born pre-term. Similarly, development is poor for any child small for gestational age, or of low birth weight. Blood vessels are poorly formed, and tend to be attenuated compared to a child born of a normal pregnancy. Of course, you may say, many will catch up as did this one. Unfortunately, catch up growth leads to more metabolic demands, and is associated with hypertension in later life. The islet cells are also poorly developed, and there is a greater risk of diabetes. What is the evidence for this? There are many studies, but I will cite only a few.

In a meta-analysis of over 2 million individuals from 31 studies, White *et al.*[1] found an 80% greater risk of albuminuria, 80% greater risk of impaired glomerular filtration rate (GFR), and 60% greater risk of end-stage renal disease in individuals who had low birth weight. In an interesting study of 20 431 people born in Helsinki between 1924 and 1944, followed up from birth to death or till the age of 86, Eriksson *et al*.[2] found that birth before 34 weeks carried a 2.6 times greater risk of developing chronic kidney disease (CKD). Zhang *et al*.[3] analysed 23 studies including 506 340 pregnancies in patients with CKD and found a greater risk of premature delivery (OR 5.72) and small for gestational age or low birth weight (OR 4.85). I will not belabour the point.

I have been a nephrologist for 52 years, and have considerable experience with treating lupus, especially as the specialty of rheumatology blossomed after nephrology, so that for much of this period all lupus was treated by nephrologists. I believe pregnancy is quite safe if the female has been in remission, and by this I mean with normal renal function and no proteinuria for a year, without immunosuppression. I would encourage females who wish to get pregnant at this stage. I believe there is around a 25% chance of foetal problems (prematurity or small for dates) if the mother requires even a small dose of medicines for lupus, and I would advise strongly against undertaking a pregnancy.

I would like you to think of a child who has renal failure. Can you imagine the trauma of growing up with diet restrictions, of taking medicines in large quantities, of the difficulties of being short, of physical disabilities in those who have osteodystrophies? Put yourself in the position of a child who has to be on dialysis while his classmates are on the field dreaming of being the next King Kohli or Hitman Sharma? I am hard put to keep from weeping when a child begs his mother for an extra helping of ice cream or a long glass of cold fruit juice that I have forbidden.

The war between paternalism and informed consent is over, and informed consent has won. The mother to be is given the facts and takes her decision. It is her life, and we cannot question her if she chooses to risk it. However, does she have a right to decide for her unborn child? I believe I have knowledge and experience that she cannot have from a fact sheet of statistics, and I believe I have a duty to be paternalistic and dissuade her strongly from undertaking pregnancy unless she is in complete remission for at least a year off medicines. If there is a flare during pregnancy, I would recommend termination if obstetrically feasible. Obviously, if she disregards my strong recommendation and still gets pregnant, I will do the best I can to ensure a safe outcome for both mother and child.

As a footnote, let me add that I continue to advise females with renal transplants to avoid pregnancy, though the vast majority of pregnancies among them are uneventful. I tell them that a transplant in our country is a very precious thing. It has cost money that most people cannot afford, and it has cost someone else a kidney since the majority of transplants in India are still from live donors. We should not take even a small risk with them. One young female with her mother's kidney, way back in the 1980s, was firm in her decision, and got pregnant despite my advice. I treated her with all the skill I have, and she had her baby and is still well, and her child has grown into a strapping young man. On every visit to me, she silently rebuked me by bringing the child along to show him to me. I am delighted

that she and her son have done well, but I still advise my patients not to undertake pregnancy.

What's in a name?

The Medical Council of India (MCI) has specified a certain number of professors and assistant professors required for the different specialties in each teaching hospital, and the Department of Tamil Nadu Medical Education promptly sanctioned and filled the posts. The problem, it turns out, is that the incumbents that now fill many of the posts have postgraduate qualifications, but not in the specialties to which they have been posted. Newspaper reports gave detailed lists of urologists being posted as anaesthetists and gastroenterologists, of ophthalmologists in cardiothoracic surgery and of ENT surgeons in neurosurgery, and so on. Apparently, the protesting doctors have been informed that they can continue to work in their own specialties though designated as something else. How that will satisfy MCI norms puzzles most of us, but the government apparently has a poor opinion of the powers of observation of the inspectors appointed by the MCI.

One of the doctors was quoted as saying that there is a financial crunch and so no extra staff have been employed. Only their designations have been changed. Meanwhile the minister proudly claimed that he planned six more medical colleges.

REFERENCES

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3 Zhang JJ, Ma XX, Hao L, Liu LJ, Lv JC, Zhang H. A systematic review and meta-analysis of outcomes of pregnancy in CKD and CKD outcomes in pregnancy. *Clin J Am Soc Nephrol* 2015;**10:**1964–78.

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