**Goyal Suman Conveying DMD carrier status of female foetus**

Reviewer 1:

I have gone through the article titled **Conveying the status of a female DMD carrier fetus - A dilemma**.

I have following suggestions, comments for the authors:

1. In Keywords I suggest add ‘sex selection’, ‘MTP’
2. Please mention in the text, Duchenne Muscular Dystrophy (DMD)
3. Little more description of the disease and what test (blood test, fluid test etc.?) is necessary for readers (particularly non-medical readers).

DMD is a fatal neuromuscular disorder caused by a recessive mutation on the X chromosome. Because the related mutation is recessive, DMD is more common in boys than in girls, as boys do not have another copy of the X chromosome to compensate for the genetic defect. DMD affects about 1 in 3,500 males. On the other hand, most girls born with DMDmutations are merely carriers, because they each possess only one mutated DMD gene on one of their two X chromosomes. Although *not themselves affected* (Authors have given explanation for this) by DMD, carriers can pass DMD genes on to their children. (*Got this para from link* <https://www.nature.com/scitable/topicpage/sex-linked-diseases-the-case-of-duchenne-800>. *I am not a medical person, authors have to check the authenticity of this information.*)

1. If DMD is more common in boys, prenatal diagnostic test will be useful in such situations too. If the test is conducted, and results are shared with the parents, they may get an option to decide either to continue or terminate the pregnancy, even when embryo or foetus is of male sex. The authors have not provided any information on this. Some statistics on this point will help readers to understand the issue in a better way.

PCPNDT prohibits sex determination of either sex - girl or boy. But the same Act allows to carry out the prenatal diagnostic test to identify genetic abnormalities or disorder (Section 4(2)(ii)) genetic metabolic diseases or sex linked genetic diseases (Section 4(2)(iv)) or any other abnormalities or diseases as may be specified by the Central Supervisory Board (Section 4(2)(vi)).

Therefore, the pre-natal diagnostic test will be allowed to be conducted under the current PCPNDT Act as DMD is sex linked genetic disease. The authors will have to argue that the girls are not necessarily only carriers but are also sufferers. So the test needs to be conducted and results have to be shared with concerned persons. Sex of the foetus should not be disclosed but the doctor may just give information about the DMD. Though there is possibility of identifying sex of the foetus, the doctor is not disclosing the sex herself but may be impliedly understood by the parents, for which the concerned doctor/person is not criminally liable under PCPNDT (Section 6 read with Section 23).

Alternatively authors will also have to argue that even though the girls may not suffer from DMD (the condition not covered by PCPNDT), they could be the carriers of DMD and hence be included specifically in Section 4 of PCPNDT. For this purpose, provision of Section 4(2)(vi) need to be invoked and Central Supervisory Board should be persuaded to bring the change through Rules/Regulations. Instead of amending the legislation viz. PCPNDT Act, changing Rules/Regulations is much easier way out and is specifically mentioned so in Section4(2)(vi) read with Section 16.

While building the argument that PCPNDT needs to be amended, it is necessary to identify which provision, clause, section needs to be amended and how. It need not be necessary to spell out legal wording of the needed amendment, but still what should be the content/substance of the amended version is necessary.

1. Please quote the relevant section of PCPNDT in foot note 1 – Sec 4 (3) (iv) or (v), sec 7/16. I would prefer it in the text instead of foot note.
2. It’s also necessary to refer to the MTP Act, 1971.
3. Currently Section 3 of MTP provides when RMP can terminate the pregnancy. Sec 3(2)(i) and (ii) allow medical termination of pregnancy. These are
4. the continuance of the pregnancy would involve a risk to the life of the pregnant woman or of **grave injury** to her physical or **mental health**; or
5. if there is a substantial risk that if the child were born, it would suffer from such physical or mental **abnormalities** as to be seriously handicapped.

Above Clause (i) and (ii) may be invoked to safeguard the RMP if she terminates the pregnancy when male foetus is found to be suffering from DMD. As per authors even when female foetus is found DMD positive (either as carrier or to be sufferer in future) is likely to be sufferer. Such foetus can be terminated under these two clauses.

However, in case of accepting alternate argument that the female foetus is just going to be carrier of DMD, there is no ground for terminating the pregnancy unless the pregnant woman mentions “failure of Contraceptive used by her” (Explanation 2 to Section 3) and refuses to disclose the true reason. (Authors need to mention here that Explanation 2 to Section 3 is available only to married women)

The argument by authors therefore could be to amend the MTP Act. (Currently MTP Bill is pending. One may suggest further changes, if need be)

1. Besides these legal arguments, reference to Homeopathy medicine, stem cells, gene based / cell based / drug based therapies also need to be covered though its efficacy could be in question.
2. Another important argument that needs to be addressed by authors is related to UNCRPD. India has ratified UN Convention on Rights of Persons with Disabilities and is under obligation not to discriminate against any person due to disability and every person with disability has right to life and live with dignity
3. Along with CRPD, it is also necessary to refer to the Rights of Persons with Disabilities Act, 2016 while arguing for termination of pregnancy on the ground of disability. The Act recognises the right of persons with disability and the Schedule clause 1 (A) (d) specifically refers to Muscular Dystrophy (MD).