

## LETTER

**Saviour siblings in India: A reminder of our existing challenges and biases**

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Saviour babies or saviour siblings are conceived specifically to be sources of biological materials — ranging from cord blood, stem cells or even organs — to save another child, usually an older sibling, who is suffering from a disease like thalassemia that can be cured with this biological material. In 2020, the media reported about the birth of India's first saviour baby, in the state of Gujarat [1]. In January 2023, there was a report of the birth of another saviour baby, in the state of Maharashtra [2]. Ethical concerns relating to saviour siblings find a place in the western bioethics discourse. However, it is little discussed in the Indian context.

Key ethical issues highlighted in the literature with regards to saviour siblings include the fact that one agent, the newborn saviour baby, is treated as a means to an end, ie, saving the elder sibling; concerns about commercialisation of human biological material and life; the risk of eugenics [3] by selecting embryos with socially desired traits; the question of respect for the agency and autonomy of the saviour baby [4]; and the impact on family dynamics and collective interests [5]. Building on these issues, we highlight concerns that are more likely to be relevant in the Indian context; these concerns are in fact pre-existing challenges pertaining to healthcare and ethics.

Firstly, planning and creating saviour siblings requires coordination and teamwork, and involves multiple healthcare specialities. Given the costs, coordination and efforts required for each case, such services are expected to be available only in private healthcare setups. We are not aware of any health insurance programme in India covering these costs. This would leave out a substantial section of our population that uses the public sector for healthcare and is largely economically marginalised.

Secondly, there are issues around shared decision-making. A study in the Indian setting found that less than 25% of parents knew that the thalassemia gene could be detected before marriage, or during a pregnancy [6]. With such limited awareness on the subject, parents may learn about the possibility of conceiving a saviour baby only if their physician is aware about this scientific advance. Given that Assisted Reproductive Technologies, which are used to conceive

saviour babies, are highly commercialised in the country and that the Indian health systems can be paternalistic, giving limited agency to patients, the risk of misuse can become more likely. These include exaggerating the success rate of the medical procedure or not involving family in shared decision-making including for spare embryos post IVF.

Further, patriarchy inside family structures in India places men and the paternal family in a position of power when it comes to reproductive decision-making. Similarly, Indian parents are known to have excessive control of their adult children's choices and decisions. These factors together limit collective decision-making within a family when it comes to choices around a saviour baby and put women and children at a disadvantage.

Overall, the possibility of a saviour sibling is a reminder of existing ethical challenges and biases. While the introduction of such new technologies can help save lives, it also highlights key health disparities, and the underlying ethical and equity issues. Attention to this broader context should also guide policies, guidelines and research relating to saviour siblings.

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