REPLY: We thank Dr Tripathy for his interest in our report on pars plana vitrectomy (PPV) for eyes with retinoblastoma refractory to all standard therapies. Indeed, there was no evidence that tumor escaped from any eye because of PPV surgery. In answer to your question, tumors were first surrounded by laser scar, delivered before the PPV and by endolaser during the PPV, which served to avoid retinal detachment. The resultant scars formed the boundary of the tumor to be resected, so no “clinically healthy” tissue was removed. The intraocular pressure was held in the boundary of the tumor to be resected, so no hypotensive anesthesia was used. Avascular tumor, we experienced no intraocular hemorrhage and did not use hypotensive anesthesia.

Our report shows that PPV was a useful contribution to the array of treatments useful to salvage eyes containing retinoblastoma. After PPV for active intraocular tumor, 18 of 21 eyes were salvaged long term with vision of ≥20/200 in 14 eyes that otherwise had failed all treatments, so the children were facing removal of their last eye. In 3 eyes, PPV failed to control the recurrent tumor. Two eyes were enucleated and showed no high-risk pathologic features.

Most important, one patient was lost to follow-up after the failure of 3 PPV surgeries, and many other treatments over 3 years to control anterior tumor. The parents refused enucleation and were lost to follow-up. In our report, we speculated that this child would likely die of retinoblastoma. We now know that indeed this child has died.

This case brings to the forefront a major cause of death of children with retinoblastoma: refusal of treatment by parents. The child in our study did not die because of complications of PPV; when last seen the tumor was clearly intraocular with 20/100 vision. It is very likely that timely enucleation would have saved the child’s life. However, the long and costly investment by the child and family into saving an eye and vision led the parents to value that dangerous eye more than the life of the child.

This problem is widespread: publicity suggesting that “no eye should ever be lost to retinoblastoma” has shifted the focus of parents and doctors from curing cancer to save a life to the cosmetic value of an eye, even an eye with no vision in a child with perfect vision in the other eye. There are mechanisms in some countries to legally overrule the parents to save the child’s life, but we understand that this is not the case in China and many other countries.

With global collaboration between all who care about children with retinoblastoma, zero deaths from retinoblastoma are feasible today. A prime area to study is how parents make choices for their child. Could better quality information at the time of first diagnosis help? The first discussion with parents about retinoblastoma would seem to be critical to establish accurate knowledge of the disease, the available treatments with their anticipated potential complications and success rates, and the value of life over retaining a dangerous, blind eye. Parents may also refuse enucleation because the 1-child policy in China has encouraged parents to seek “sound” children, and there is a low tolerance of physical disability.

Many highly productive citizens around the world lead full lives with no eyes because of retinoblastoma and other causes. Could blind survivors of retinoblastoma be mentors for families facing these issues? Can a well-informed social media help to support parents of children newly diagnosed with retinoblastoma? Can eye doctors and health workers become advocates for the child’s life without eyes, not only for the eye(s)? Can opportunities be advanced for blind children to thrive and contribute fully to society, everywhere?

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