

## Is Cost of Treatment the Main Barrier to Uptake of Retinoblastoma Treatment?

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**Introduction:** Retinoblastoma is the commonest intraocular malignancy in childhood.<sup>1</sup> It is treatable with survival rates of up to 90% in developed countries.<sup>2</sup> Mortality rate is between 39-75% in some African/Asian countries largely due to late detection and insufficient healthcare measures.<sup>3</sup> Low treatment uptake has been reported in Nigeria,<sup>4,5,6</sup> and, high cost of treatment has been considered a significant barrier to treatment.<sup>7,8,9</sup> Other identified barriers to treatment include cost of transportation, inaccessibility to standard health institutions, fear of poor aesthetic outcome, patronage of alternative medicine, and scarcity of skilled human resources.<sup>10</sup>

**Case Report:** We report three patients with retinoblastoma whose parents abandoned their healthcare under a free treatment programme. They represent 50% of patients that presented for treatment during the period.

### Patient 1:

A 14-month-old male, brought to the Eye Clinic by mother with eight month history of leucocoria in the left eye. Indirect ophthalmoscopy showed pearly white masses and no vitreous seeding in the right eye, as well as total retinal detachment with intraocular masses and vitreous seeding in the left eye. Ocular ultrasound showed bilateral intraocular retinoblastoma and an assessment of bilateral retinoblastoma (RE group C, LE group E) was made. His mother was counselled on the treatment plan of chemo-reduction, surgery and further chemotherapy at no direct cost. She however, defaulted thereafter and refused to come back despite numerous telephone calls to her.

### Patient 2:

A 4-year-old, male, brought by grandmother with a six-month history of leucocoria in the right eye, and three-month history of painful swollen right eye. Clinical examination and radiological evaluation were suggestive of right orbital retinoblastoma and he was planned for chemo-reduction and enucleation at no direct cost. The parent agreed to the treatment plan after counseling, but defaulted thereafter and refused to come back despite numerous telephone calls to her.

### Patient 3:

A 3-year-old female, was brought by grandmother with history of leucocoria in the left eye of a month duration. Clinical examination and radiological evaluation were suggestive of left orbital retinoblastoma. She was planned for chemo-reduction and surgery at no direct cost, a plan to which the parent agreed. However, she defaulted thereafter and remained unreachable.

**Discussion:** Treatment abandonment is a major concern in treatment of retinoblastoma. It is reported to be up to 50%.<sup>7</sup> Financial constraint is a major reason for treatment abandonment.<sup>7,8,9</sup> In Nigeria, anecdotal reports suggest that cost of treatment results in low treatment uptake. However, findings from our case series suggest that there are other major barriers to the uptake of treatment for retinoblastoma. A possible reason for treatment abandonment in our series is the absence of the patients' fathers during counselling, since culturally, the final decision regarding the treatment of children rests with the father. Other reasons include cultural beliefs/misbeliefs associated with retinoblastoma, and poor health-seeking behavior of patients in this environment.

**Conclusion:** The cost of treatment is a barrier to uptake of retinoblastoma care, however, other factors such as cultural beliefs, family structures with limited roles for women in decision making, poor health seeking behaviour, may be equally important, and these have to be addressed to ensure effective treatment delivery.

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