

Influence of Socioeconomic and Cultural Factors on Retinoblastoma Management

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Retinoblastoma (RB) is the most common intraocular malignancy of childhood. It contributes to 4% of all pediatric cancers.^[1] The incidence of RB is 1 in 15,000–18,000 live births.^[2] According to the data published recently by the American Cancer Society, 280 new cases of RB have registered annually in the USA.^[3] The age-adjusted incidence rate (<5 years) in the USA is 4.2 per million population (under 15 years).^[4] Two decades ago, according to the Bombay Cancer Registry, the incidence in India was more or less similar to that in the developed countries, with 4.2 cases per million population in <15 years age group.^[5] However, over the last two decades, the number of cases has increased, possibly due to increased awareness, accessibility to health facilities, and better diagnostic tools. According to a recent report, about 1600–1800 new cases are diagnosed in India every year.^[6]

RB is a potentially curable tumor with high survival rates if treated early and appropriately. With the advent of improved focal therapy, local routes of drug delivery, and

multimodal therapy for orbital RB, the survival with RB has improved dramatically. Other factors that have improved survival are increasing awareness, early diagnosis, and timely referral to specialized care centers.

Although overall survival rates have improved, there is still a huge gap in survival rates between the developed and the developing nations. One major factor for this is the stage at presentation. In developing nations, advanced disease contributes to 30%–40% of all cases, whereas in developed nations, only 2%–5% cases of RB have advanced disease. Hence, the survival rates are as high as 90%–99% in the developed nations^[7,8] while only 50% of children with RB survive worldwide.^[8–11]

Several socioeconomic factors contribute to advanced stage at presentation due to delay in diagnosis, lack of access to healthcare facilities, ignorance about early signs, illiteracy, poverty, lack of trained personnel, and inadequate infrastructure. Cultural factors also influence treatment decisions and their uptake.

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Socioeconomic Factors

Various studies have shown that patients with a lower socioeconomic status were less likely to receive the recommended therapy and experience less favorable outcomes as compared to those with a higher socioeconomic status.^[12] Some of the ways in which socioeconomic status affects treatment and prognosis are as follows:

- a. Due to economic constraints, parents from low socioeconomic strata are unable to travel to a specialized center in the early stages of disease, resulting in disease progression, with resultant worsening prognosis
- b. Appropriate treatment may not be accessible due to scarcity of human resources, unavailability of appropriate diagnostic skills and instrumentation, essential medication, and lack of support from government and nongovernmental organizations (NGOs)
- c. Prolonged treatment protocols that require lengthy stay away from home are another deterrent. Registry-based studies have shown that survival after childhood cancer depends on the resources of the families. The presence of siblings may affect patient care as parents can devote less time in assisting a sick child and there is also less to spend on each child, thereby increasing the chances of comorbidities before and after diagnosis^[7,8]
- d. Few specialized centers have the facility for treatment and these are also located only in the big cities, away from rural areas and smaller towns
- e. Socioeconomic status also has an influence on the level of education. Parents with a lower status have limited information regarding the signs and symptoms of RB. Parents often state that even though they noted an abnormality in the eye, most often the white reflex, they did not relate this to the possibility of having a life-threatening disease. On the other hand, parents with a higher educational level have a better level of overall health literacy and awareness
- f. Comorbidities are more prevalent in children from lower socioeconomic strata due to lack of immunization, respiratory infections, malnutrition, and other factors that further compromise the overall survival rate.

Cultural Beliefs

These are also likely to influence treatment decisions as follows:

- a. Due to advanced disease at presentation, enucleation is the most commonly offered treatment. Often, it is not accepted due to unfounded fear of cosmetic disfigurement. This is especially true for a female child, where the cosmetic disability may hinder marital prospects

- b. Alternative systems of medicine such as Ayurveda and Homeopathy are quite popular and on many occasions, they are preferred over the cosmetically disfiguring surgery of enucleation
- c. Gender-preferential treatment – If the affected child is a male, the family is more willing to borrow for travel and treatment. On the other hand, the female child is often a victim of neglect. Although there is no gender predilection for development of RB, in a recently published study from our center, 60% of children were males, suggesting that parents are more likely to seek tertiary care services for boys than for girls
- d. Case studies of defaulters from our center who later progressed to more advanced disease suggest that socioeconomic and/or cultural factors served as deterrents in following medical advice [Table 1].

Overcoming the Barriers

Some steps that have been taken to overcome these barriers include as follows:

- a. Funding support: As the largest tertiary care referral center in India, 250–300 cases of RB are diagnosed every year. The majority of our patients are from low socioeconomic strata and rural background, reflecting the overall population demographics. The majority travel large distances for treatment. With the help of support from governmental agencies and NGOs, we have developed a model that enables free of cost treatment to the poor patients. This includes surgery, hospital stay, focal therapy, chemotherapy, and investigations. In addition, travel and logistics support are also provided. Due to efforts in this direction, the compliance toward treatment has improved drastically and abandonment rates have dropped significantly
- b. Multidisciplinary team: Treatment of RB requires close coordination between several disciplines of medicine. A team of specialists consisting of ocular oncologist, pediatric oncologist, radiation oncologist, anesthetist, radiologist, pathologist, geneticist, and nurses works together so that the desired treatment is completed under one roof. This also helps improve patient compliance and reduces the cost
- c. Counseling: Proper counseling plays a very important role in overcoming these barriers. Counseling of parents about the nature of the disease, importance of early treatment, available treatment options, morbidity associated with the treatment which may include visual impairment and cosmetic deformity secondary to enucleation or irradiation of the orbital region, and the need for regular follow-up is important. Nursing staff and social workers play an important role in counseling the patients and motivating them. At our center, we have

Table 1: Specific case studies of defaulters due to socioeconomic and/or cultural factors

Age (years)	Sex	Diagnosis at presentation		Advice	Duration of follow-up (months)	Status at next visit	Socioeconomic/cultural factors
		OD	OS				
4	Female	Group E RB*	WNL	OD-enucleation	10	Extraocular RB OD	Female child Stigma for enucleation Cosmesis Illiteracy Preference for alternative medicine
4	Female	Group B RB*	WNL	Systemic chemotherapy Focal therapy	7	Group E RB* OD	Lengthy duration of treatment Poverty Long distance of travel Female child
5	Female	Group D RB*	Enucleated	Systemic chemotherapy Focal therapy	4	Extraocular RB OD	Female child Poverty Lengthy duration of treatment Illiteracy
2	Male	Group B RB*	Enucleated	Systemic chemotherapy Focal therapy	8	Extraocular RB OD	Illiteracy Long distance of travel Preference for alternative medicine
3	Male	WNL	Group E RB*	OS-enucleation	6	Extraocular RB with lymph node invasion	Stigma for enucleation Preference for alternative medicine

*The International Classification System for Intraocular RB. RB: Retinoblastoma, WNL: Within normal limit, OD: Right eye, OS: Left eye

a dedicated social worker and staff nurse for patients with RB who track patient's follow-up by contacting the families by phone before appointment and if they do not return for their scheduled appointment. This has resulted in a significant decrease in dropouts after initiation of treatment.^[13]

What More Can Be Done?

- RB has a definite recognizable early stage, where focal therapy and/or chemotherapy alone suffice. Sensitizing ophthalmologists and pediatricians toward detection of this vital sign must be undertaken. Linking the "red reflex test" with the national immunization program can go a long way in screening children and identifying them
- A nationwide awareness campaign to educate the public and healthcare professionals about early signs of RB is required.^[13] Early detection of RB and appropriate referral to specialized centers will help in proper treatment and follow-up of these cases
- The use of telemedicine for continuing education and consultation^[14]
- Identification of a modern center that could mentor other centers using a twinning model, wherein there is a direct and continuous interaction between peripheral hospitals and a specialized center through education, training, and telemedicine^[15]
- Improving the infrastructure and imparting specific training to postgraduate doctors and primary physicians^[16]
- Global initiatives by NGOs such as the International Network for Cancer Treatment and Research, Orbis International, and the International Agency for Prevention of Blindness should be encouraged

- Creation of facilities for diagnosing and treating RB at the primary and secondary levels of health care can help reduce mortality and morbidity.^[7]

Summary

RB accounts for a high tumor burden in developing countries, and the prognosis is closely related to the socioeconomic and cultural profile of the population. Socioeconomic and cultural factors directly affect disease progression and final treatment outcomes. These barriers can be overcome to a certain extent by improving awareness about the disease, proper counseling of parents, providing free of cost treatment to patients from low socioeconomic strata, and raising funds by involving governmental NGOs.

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Conflicts of interest

There are no conflicts of interest.

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