

Letter to the Editor

Late effects of treatment in survivors of retinoblastoma in India: Are we on the road to recovery?

DOI: 10.4103/2278-330X.179688

Dear Editor,

We read with interest an article entitled “Late effects of treatment in survivors of childhood cancer from a tertiary cancer center in South India”.^[1] It is a well-written and comprehensive research article related to late adverse effects

of both childhood cancer and its therapy in survivors in India. The work conducted by Rajendranath *et al.*,^[1] is commendable as they have retrospectively studied the cancer cases, which were diagnosed long back in 1968 till 2001. Since then, healthcare infrastructure and medical technology has advanced so much that the complications once associated with the treatment of various cancers are not seen now. But, after thoroughly going through the article, we realized that the scenario for retinoblastoma patients has not changed much in India.

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Rajendranath *et al.*,^[1] have mentioned that out of 155 cancer survivors, two had retinoblastoma, for which they had undergone enucleation along with chemotherapy and high dose external beam radiotherapy of 40-50 Gy and out of these two patients, one with bilateral retinoblastoma diagnosed in 1968 presented with secondary neoplasm after 37 years. The noteworthy findings mentioned here are underreporting of retinoblastoma cases (1.2%), need of enucleation and chemoradiotherapy for treatment along with necessity of long-term follow up for keeping vigilance over development of secondary neoplasms. But what is disappointing is that presently also, most of our retinoblastoma patients have to undergone enucleation as a part of their treatment. This draws attention to the fact that we are using the same treatment strategy in the present day that we were using about 50 years ago. This is mainly due to late presentation, delay in diagnosis and poor compliance to therapy, compounded by the lack of an ideal multidisciplinary team required for treatment of retinoblastoma.^[2] Whereas, ocular salvage is the primary concern in the developed world, death from retinoblastoma is still common in developing countries^[2] and we are still struggling to save the lives of these unfortunate children, which also sometimes becomes impossible in few advanced cases or in cases of abandonment of therapy during treatment.

We are about quarter a century lagging behind in medical technology as compared to the developed countries where enucleation is obsolete and intra-arterial chemotherapy and intensity-modulated radiation therapy have emerged as new therapeutic approaches along with embryo screening as an earliest possible way to diagnose retinoblastoma.^[3] Taking a step ahead toward better and standard management, Indian Council of Medical Research released the National Guidelines for Management of Retinoblastoma in 2010, but we have noticed that at many institutions, the treatment protocol is not being followed stringently. Almost 50% of the patients do not have an intraocular implant placement post-enucleation and only a small percentage of cases seek prosthetic rehabilitation with an ocular prosthesis post-enucleation, which worsens their quality of life and results in late complication associated with enucleation that is post-enucleation socket syndrome,^[4] facial asymmetry, and cosmetic deformity coupled with psychological distress, social neglect, and stigmatization.

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How to cite this article: Aggarwal H, Kumar P. Late effects of treatment in survivors of retinoblastoma in India: Are we on the road to recovery?. *South Asian J Cancer* 2016;5:22,26,36.