

Post Enucleation Functional Vision Assessment in Retinoblastoma Survivors. A Neglected Aspect in Management Plan!

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Little is known about the impact of treatment in retinoblastoma (RB) survivors in terms of disabilities which may cause hindrance in taking part in daily life activities. Van Dijk et al reported that 55% of the RB survivors perceive RB-related restrictions in their routine life activities related to their school, professional career, mobility, or self-care, etc.¹ Weintraub and colleagues also found negative correlations between motor functions and children's quality of life (QOL) who survived RB treatment and have monocular vision.²

Retinoblastoma is a most common curable primary ocular tumour in paediatrics age group with high survival outcome if treated appropriately in time. Although the outcomes of RB treatment have improved globally, large variation persists in the clinical presentation and survival outcomes of the affected children between higher-income and lower-income countries, with some regions having major survival gaps.³ This variance is being further noticed among the low-income countries of Asia-Pacific region.⁴ Several factors are being described in literature that contribute to this in consistency. Awareness issues, lack of trained primary health care workers, socio-economic constraints and cultural beliefs are a few to be mentioned.⁵ Moreover, it is

reported that children from rural or low-income background are less likely to receive the recommended therapy due to inaccessibility to specialized health services located in first-tier cities. Consequently, a large number of patients when present in hospitals are already afflicted with advanced disease (International Retinoblastoma Classification Groups D and E).⁶ Therefore, enucleation becomes the only treatment recourse remained to offer to parents despite availability of globe-sparing treatment options in low-income countries like Pakistan.

There is a plausible connection being reported between the retinoblastoma survivors, who had unilateral enucleation or exenteration, and QoL. The visual system is a key component in the normal growth of a child. In literature there is a well described relationship stated between visual system and development of motor functions in young children.⁷ Motor functions are pivotal, enabling children to conduct everyday tasks (e.g., dressing, eating, mobility), to refine their fine skills i.e., in academics (e.g., writing) and help in execution of precise and targeted movement in playgrounds (e.g., catching ball, jumping, and running). Contrarily monocular vision in young children influences negatively in attaining both gross and fine-motor skills, eye-hand coordination as well as mobility.^{1,8} Therefore, post enucleation monocular vision is an important determinant that influences motor skills in RB survivors and has a negative relationship on their QoL. Post enucleation visual-motor-coordination deficit is found in approximately 40% of children aged three years and younger. These children found difficulties in performing daily life activities such as street crossing

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due to the affected motion processing abilities, difficulties with depth perception and judgement of the distances.^{9,10} Thus, it is important to understand the implications of enucleation in young survivors of RB.

While we are plagued with multiple high priority diseases in children e.g., diarrhoea, typhoid, flu, chickenpox, pneumonia more than RB (relatively rare disease), it is not surprising to find that the impact of visual impairment on the motor function and QoL has received little attention in children with visual impairment in general and in RB survivors in particular. It is time to address in our rehabilitation plans, the consequential developmental and psychosocial as well as vision related issues specifically those associated with physical and/or academic QOL to help these children take part in life mainstream activities.

Firstly, as part of a holistic approach, it is imperative for clinician and health professionals who are engaged in the management of retinoblastoma to understand the extent of motor difficulties among survivors of RB with monocular vision and determine the relationship between motor function and QOL (both vision-related and overall health-related).

Since RB affects young children below 5 years of age, vision assessment techniques are tailored to this age group in our routine management protocols. These are mainly focused only to assess the impact of ongoing treatment i.e., systemic chemotherapy and local chemotherapy in cases of unilateral or bilateral disease respectively on visual acuity of the non-enucleated eye. It is recommended to incorporate functional vision evaluation in our RB management guidelines.

In summary, it is important for the RB teams to be aware of the ramifications of enucleation both from a psychosocial standpoint and about the impact of monocular vision after unilateral enucleation. There is a dire need to establish comprehensive rehabilitation protocols for retinoblastoma survivors at national and international levels for timely detection of motor deficits and to initiate appropriate therapeutic interventions.

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