Children’s Visual Impairment: Do We Really Need Quality of Life Questionnaires?

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In the recent past, vision-specific quality of life (QoL) questionnaires have come to fore for various eye diseases including glaucoma and dry eye. For children with visual impairment for various reasons, one such questionnaire was the Children’s Visual Function Questionnaire for children 3 years and beyond (CFVQ3plus)\(^1\) which was translated into Filipino and validated in an earlier study by Lee et al.\(^2\) This was the questionnaire that was used by Buño and Pajarillo\(^3\) to determine the effect of visual impairment in the 3-7 age group. The questionnaire assessed general health, general vision, competence, personality, family impact, and treatment. They found a lower total index QoL scores for general vision, competence, and personality compared to age-matched controls, when parents or guardians completed the questionnaires.

Do we really need this type of questionnaire? What purposes do this achieve? What do we do with this information? For many authors including Buño and Pajarillo, QoL questionnaires “measure the impact of both disease and treatment on the child’s (also the patient) life, self-esteem, activities of daily living, social interactions, emotional well-being, and independence.”\(^3,4\) This becomes glaringly more significant in children who have a full life ahead, affecting not only their psychosocial health but also their educational experience, and future career choices.\(^5\)

Children and their parents or caregivers, however, may have differing perceptions of the impact of an illness on QoL. Parents can either under- or overestimate the impact of disease compared with the response of a child directly affected with the visual impairment.\(^6\) As such, both the child, when able (typically around age 5), and the caregiver should accomplish such QoL questionnaires to create a clearer picture of what truly transpires in the home of every child with visual impairment. Parental factors such as their own health and well-being, age, gender, educational level, socioeconomic status, number of other children, ethnicity, and extended family support should also be evaluated.\(^6\) Concordance may also vary based on the child’s diagnosis, severity of disease, age, gender, onset of disease, duration of illness, and treatment status.\(^5\)

Ideally, all such data should be collated for a more reliable view of the true picture and impact of visual impairment. QoL studies can estimate the burden of disease at an individual, parental, community or societal level, and even at the national level especially with the advent of increasing number of children claiming visual disability, and the country’s upcoming universal healthcare law that covers not only treatment but also rehabilitation.\(^6,7\) Results of this type of studies can only influence national health policy formulation and interventions, such as developing pediatric vision screening program, public health interventions, and rehabilitation strategies if and only if it becomes routine and common place for all pediatric eye care professionals to obtain both the patient’s and the caregiver’s responses to QoL questionnaires. This is the challenge posed to all pediatric-inclined eye care professionals - to come together in obtaining QoL
data, collate all information into a national database, and perform research on such data - if we are to truly improve on the QoL of all children living with a visual impairment.

REFERENCES