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EVIDENCE TO PRACTICE COMMENTARY

Health-Related Quality of Life among children with disabilities: is there a place for parent-proxy reports? A Commentary on the "The Effects of Basic Photography Education on Quality of Life, Self-Esteem, Life Satisfaction and Moods in Children with Diplegic Cerebral Palsy: A Randomized Controlled Study"

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The study by Alkan and colleauges (2021) investigated the effect of an 8-week basic photography education program on Health-Related Quality of Life (HRQoL), among other outcomes, in children and adolescents aged 10 to 19 years with diplegic cerebral palsy and mild disability profiles. The study suggests that the participation in the training program may have a positive short-term effect on HRQoL from the child's perspective, but not the parents'. This result raises several questions, but above all provides an opportunity to reaffirm the importance of considering quality of life as a key outcome when evaluating interventions, and more broadly in epidemiological studies among children with disabilities. HRQoL is a multidimensional construct that reflects the subjective perception of the patient's health status, including physical, emotional, and social components in line with the World Health Organization's (WHO) definition of health. An emphasis on the importance of understanding patients' views on their care including the effectiveness of interventions on children's or adolescents' HRQoL has led to its increasing use in pediatric clinical trials. Furthermore, there is now recognition of the need to capture the changes in health that matter most to patients; therefore, patients' views on their treatment/care are also increasingly sought in clinical practice.

A main question raised by the Alkan and colleagues (2021) study concerns the value of parent-proxy reports, which did not capture the benefits of the intervention perceived by the children. HRQoL

is by definition subjective and should be assessed from the individual's perspective whenever possible. However, when this is not possible, due to the child age or cognitive abilities, the parents' perspective is used as a proxy. In this case the parent's proxy report is intended to represent the child's perspective as closely as possible. However, consistency between self-report and proxy-report has been investigated over the past decades and agreement has generally been shown to be low to moderate. In general, parents proxy-report lower scores than those of their children, and differences between raters tend to increase in areas covering subjective appraisals of life, such as social relationships and emotional feelings (Sentenac, Rapp, Ehlinger, Colver, Thyen, & Arnaud, 2021). While these findings may lead some to discredit parent reports, parent-proxy HRQoL can provide valuable information as long as their limits are understood. They do not suggest that parents are not suitable respondents, rather highlight the importance of considering the multidimensional nature of HRQoL. Of particular interest are studies that have looked at patterns of discrepancies and have investigated factors that might explain the magnitude of discrepancies. First, child-parent discrepancies in reporting HRQoL are strongly related to the nature, severity and pain associated with the child's health conditions (Sentenac et al., 2021). Of even less magnitude, social desirability, a phenomenon well documented in the literature, especially in children, is often responsible for an underestimation of psychological symptoms when they are self-reported (Logan, Claar, & Scharff, 2008). Interestingly, parental psychological distress has also been shown to be crucial in explaining part of the distorted perspective that parents have of their child's HRQoL (Sentenac et al., 2021; Eiser & Varni, 2013). Parental depression or highly emotionally invested situations are factors associated with larger discrepancies between parents' and children's views. Proxy-reported HRQoL by parents is also related to poor parenting experience, as measured by parental stress, and poor adjustment to the child's chronic condition, especially mothers who are more often involved in daily care (Eiser & Varni, 2013).

Finally, we must consider what can be learned from assessing changes in HRQoL after an intervention, a treatment or over time. In their study, Alkan and colleagues (2021) examined the potential effect of participation in arts-oriented leisure activities on HRQoL. Participation in such activities has the potential to improve feelings of self-confidence, self-esteem, fairness, and socialisation with a potential impact on psychological, emotional and social well-being (Dahan-Oliel,

Shikako-Thomas & Majnemer, 2012), with a lesser impact on the child's physical well-being and autonomy. We can therefore expect that the different dimensions of HRQoL are not impacted in the same way based on the intervention, which could be one of the possible reasons for the discrepancies between parent proxy- and self-reported HRQoL. In other words, the potential effect on HRQoL attributable to the educational program observed in the self-reports may only influence the more subjective domains which are less likely to be perceived and reported by parents compared to changes in observable behaviour. The results presented on median total HRQoL scores do not allow for interpretation of changes in specific domains; but, findings on secondary outcomes can confirm the positive effect of the intervention on self-esteem and life satisfaction. The choice of instrument is therefore crucial and must address pre-specified hypotheses about where the intervention might be most effective.

Overall, it is clear that the child's perspective should be privileged in all cases where an intervention is directed towards improving emotional or social well-being due to the numerous influences that may lead to discrepancies between self and proxy-report. Furthermore, careful consideration of the match between the expected domain changes in HRQoL following intervention and the instrument used to measure change is needed in both research and clinical practice.

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