

What are the factors that adolescents with cerebral palsy perceive as important for their quality of life?

childhood
disability
LINK



Summary

This study involved adolescents (12-16 years old) with Cerebral Palsy. Twelve adolescents were interviewed individually, using a semistructured, open-ended format, and were asked to give their opinion on the extent to which factors such as their personality, features of cerebral palsy, family, friends, school and community made a difference in their satisfaction with life. Their answers were classified into intrinsic (related to the adolescent) and extrinsic (related to the environment) categories. Participants reflected on their quality of life as an interaction between intrinsic and extrinsic factors. The predominant theme that emerged involved a relationship between personal interests and preferences, and opportunities to participate in age-appropriate activities and leisure activities. Indeed, according to the adolescents, opportunities to participate in a variety of activities that they value contribute to a better satisfaction with life, regardless of their level of motor impairment. The factors related to the disability in itself were not considered by adolescents as detrimental to a good quality of life. Accessibility to preferred activities (availability of opportunities, spaces and programs) and the ability to manage problems and self-advocate were perceived as important to having a good life quality.

What practitioners should know

From the adolescent with cerebral palsy's perspective, disability characteristics are not an important factor influencing quality of life. Participation in leisure activities, especially activities that they have chosen, is very important for an adolescent's satisfaction with life. Health care professionals and family members should take into account adolescents' preferences when planning interventions

and promoting programs aimed at improving their quality of life. Adolescents with cerebral palsy enjoy participating in a range of activities in both integrated (with peers without disabilities) and segregated (with peers with disabilities) environments. The identification of factors that can be modified, such as accessibility to services, competence (e.g. self-esteem, management of challenges), and preference for different activities may help professionals to advocate for greater participation in these activities and tailor individual therapeutic strategies accordingly, increasing the likelihood of enhancing the quality of life of this population.

Reference

Shikako-Thomas, K., Lach, L., Majnemer, A., Nimignou, J., Cameron, K., Shevell, M. (2009). Quality of life from the perspective of adolescents with cerebral palsy: "I just think I'm a normal kid, I just happen to have a disability". *Quality of Life Research*, 18, 825-832.

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