

Oral presentation

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The meaning of quality of life in adolescents with spina bifida and their parents

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Background

Children and adolescents with complex neurological conditions require a holistic approach to care in order to achieve two major distinct outcomes, condition management and quality of life (QOL). However, the meaning of QOL for adolescents with spina bifida (SB) and their families has not been well delineated. This preliminary analysis, a part of a larger study of adaptation and secondary conditions in SB, addresses quality of life from the perspective of the adolescent living with SB and his/her parent.

Materials and methods

A correlational descriptive study of 100 adolescents with SB 12–21 years of age and their parents was conducted using telephone interviews. All adolescents reported on SB Health Related Quality of Life Tool (HRQOL) and they and their parents reported on three single items of overall QOL (adolescent QOL, parent QOL, and family QOL). The HRQOL tool uses a 1–5 scale and has good reliability ($\alpha = .85$). The single items use a 0–100 scale. Open ended questions were used to gather data on what QOL means and what goes into making a good QOL.

Results

All quantitative measures of HRQOL and QOL were positive and generally fairly high. The mean values were: HRQOL $M = 4.2$ ($SD = 0.48$), adolescent report of their QOL $M = 85.54$ ($SD = 22.39$), their parent's QOL $M = 87.67$ ($SD = 19.96$) and their family's QOL $M = 86.55$ ($SD = 20.84$) and parent report of their adolescents QOL $M = 77.91$ ($SD = 17.49$), their own QOL $M = 82.07$ ($SD = 16.77$) and family QOL $M = 82.32$ ($SD = 17.46$). However, the relationship of HRQOL and adolescent overall QOL were general modest (adolescent $r = 0.26$ $p = 0.01$; parent $r = 0.32$ $p = 0.01$). The qualitative data indicated that although adolescents occasionally mentioned health or independence (and rarely SB specifically) most cited happiness, friends, family, education or fiscal factors as determinants of QOL. Parents, although more likely to mention health, independence and SB specifically, also focused on the larger picture of individual happiness, family togetherness, school and job.

Conclusion

In addition to optimal clinical management of SB, health care providers need to assess the meaning of QOL for adolescents and their families and seek interventions at the individual and policy level that address these perceptions.