

Uncovered: infant open-heart surgery and the mental well-being of parents.

childhood
disability
LINK



Glossary of Terms

- **Quality of life:** Quality of life is defined as an individual's perception of their well-being and general satisfaction with life.

Summary

Infants born with a heart condition and who survive open-heart surgery may be at risk for later developmental and behavioral problems. These risks may affect not only their quality of life, but also the quality of life of those around them. The aim of this study was to look at the health-related quality of life of children with congenital heart problems that required early surgery, and to describe the levels of stress experienced by their parents. Parents completed a questionnaire answering questions about their child and also about their own levels of parental stress.

The researchers found that the child's quality of life was no different from typically developing peers. However, over one quarter of parents indicated that they experienced higher stress levels, and a smaller number expressed denial in their stress levels.

In terms of child health, the scientists found that physical problems or motor delays were predicted by an abnormal neurologic examination at the time of surgery in the first days or months of life. Behavioral difficulties at school entry, whether internalizing (withdrawn,

anxious, depressed) or externalizing (low attention span, aggressive) behaviors, were linked to lower psychological well-being.

The researchers' findings suggest that while quality of life is often good for children who survive early open-heart surgery at school entry, behavioral problems can be associated with lower psychological scores and may contribute to higher levels of parental stress.

What families and practitioners should know

Parents can be reassured that most children who have experienced open-heart surgery early in their lives have a good quality of life later on. However, one exception is when a child experiences behavioral difficulties. This can be linked to lower wellbeing and to greater parental stress, and should therefore be carefully screened for and addressed by health practitioners. Pharmacologic and therapeutic (individual and group) interventions should be considered to minimize any internalizing and externalizing behaviors, as they may impact family well-being.

Reference

Majnemer, A., Limperopoulos, C., Shevell, M., Rohlicek, C., Rosenblatt, B., & Tchervenkov, C. (2006). Health and well-being of children with congenital cardiac malformation, and their families, following open-heart surgery. *Cardiology in the Young*, 16, 157-164.

