



Study: Kids with cardiac devices and the families have poor quality life

News

Pixel Sweatshop

December 5, 2012

0

This article was posted on the theheart.org website on December 4, 2012.

Cincinnati, OH – Children and adolescents with pacemakers and implantable cardiac defibrillators (ICDs)—and their parents—suffer from a poorer quality of life than both healthy children and patients with mild forms of congenital heart disease, a new study reveals [[1](#)]. Whether lives could be improved with the use of psychotherapy needs to be assessed in this population, say Dr Richard J Czonek (Cincinnati Children's Hospital Medical Center, OH) and colleagues in their paper published online December 4, 2012 in *Circulation: Arrhythmia and Electrophysiology*.

The work also indicates that the kids and their parents suffer from different stresses, say the authors. Devices most affected the self-perception, self-worth, and athletic capability of the children, but for parents, the biggest factor by far was their child's behavior.

"The take-home message is that devices in general certainly do impact quality of life, defibrillators more than pacemakers," Czonek told [heartwire](#). The research suggests that pediatric cardiologists and electrophysiologists need to do a better job of advising patients and their families about the impact such devices will have on their lives, he says. "We do a good job of explaining the risks of the procedure, but prior to the device being implanted we need to counsel patients about how they will feel about themselves afterward" and prepare their families for these changes, he explains.

"It's not just important what we clinically do to our patients, it's important to understand how we can also help them cope with what we do to them."

"I don't think these findings are surprising, but they are important," says past chair of the AHA Council on Cardiovascular Disease in the Young, Dr Michael Gewitz (Maria Fareri Children's Hospital at Westchester Medical Center, Valhalla, NY), who was not involved in this study. "They point out the need for medical providers to better understand the impact of what we do to save a life. It can have a long-lasting impact on the psychosocial development of children, which needs to be recognized and considered. We need to bring up the topic for discussion: it's not just important what we clinically do to our patients, it's important to understand how we can also help them cope with what we do to them."

Synergistic detrimental effect of congenital heart disease and device

Czonek and colleagues note that there has been increasing utilization of devices such as

ICDs and pacemakers within pediatric populations, but little study on the psychosocial impact of living with these. Complications that can arise following device implantation include the need for generator and lead revision and lifestyle modifications such as activity restrictions and cosmetic changes.

They performed a retrospective cross-sectional study at eight pediatric centers in the US in children aged eight to 18 years of age who had either a pacemaker or a defibrillator implanted; 173 patient-parent pairs (40 defibrillators and 133 pacemakers) completed the Pediatric Quality of Life Inventory (PedsQL) and the Pediatric Cardiac Quality of Life Inventory (PCQLI).

Quality-of-life outcomes were compared with healthy controls and patients with various forms of congenital heart disease. Compared with the healthy kids, patients with devices and their parents reported significantly lower PedsQL scoring.

Likewise, compared with patients with mild forms of congenital heart disease, patients with devices and their parents reported significantly lower PCQLI scores; those with more severe congenital heart disease but no device had similar scores on the PCQLI to those with devices, however.

The researchers note that in the group of patients studied, the presence of concomitant congenital heart disease was relatively high, especially in the pacemaker group, in which nearly 60% of patients had associated congenital heart disease. In the presence of congenital heart disease, pacemaker patients had significantly lower PCQLI scores compared with mild forms of congenital heart disease such as isolated bicuspid aortic valve (BAV) and scores comparable to patients with tetralogy of Fallot and Fontan physiology.

"In this patient population of congenital heart disease plus devices, you are taking an already pretty high-risk patient with heart disease and now adding an additional stress of a pacing system or a defibrillator system," Czosek commented.

"This study underscores the synergistic detrimental effects of congenital heart disease on the quality of life of patients with devices," he and his colleagues point out.

High rate of complications; 50% of ICD shocks inappropriate

Also, both device groups had a high rate of device-related complications, which added additional concerns for an already high-risk group.

For example, there was a high rate of ICD shocks in this pediatric cohort, they note, and nearly 50% were inappropriate. Unfortunately, the researchers were unable to make comparisons of quality of life between patients with a history of appropriate vs inappropriate device shock, due to inadequate sample size.

"Although the precise mechanisms behind lower quality-of-life scores in ICD systems cannot be elucidated in this retrospective analysis, several potential causes include larger device generator, underlying disease mechanisms, and the potential for device shock," the researchers observe.

Valuable lesson to address both parental and patient concerns

Czosek says the fact that parents and patients appear to react differently to device

implantation needs to be taken into account by doctors. “How this quality of life manifests itself is very different depending on whether you are talking to the parent or the patient. For children, it’s based on self-perception: do they feel different from other kids? For parents, they didn’t really perceive that their child felt differently. What their quality of life was driven by was their child’s behavior.”

“For children, it’s based on self-perception: do they feel different from other kids? For parents, their quality of life was driven by their child’s behavior.”

Gewitz agrees wholeheartedly: “It’s important to understand that there’s a difference between the parents and the children in what they perceive as the effects and how they manage these issues. It’s not sufficient to look at the child or teenager and deal with them; we need to deal with the entire family community, and that’s a valuable lesson. We as physicians will have to address both the parental concerns as well as the patient concerns, and somewhat differently.”

And he stresses that it is important to recognize that these patients and their families need to be continually monitored. “There needs to be an ongoing, protracted understanding of the impact and how to help the children and the families deal with it.” Currently, attempts to do this across pediatric facilities in the US “are inconsistent,” he says. “These data indicate that, even at the largest centers in our country, there hasn’t been ample focus on this aspect of care.”

“Even at the largest centers in our country, there hasn’t been ample focus on this aspect of care.”

Czosek says in Cincinnati, they are starting to address this, with, for example, the advent of a neurodevelopmental clinic for pediatric cardiology, employing cardiologists, neurologists, geneticists, and psychiatrists, who will identify any problems with behavior. “Obviously one of the groups we need to look at very closely is those kids with devices.”

They also sometimes employ mentors, although not in any organized or official capacity, he notes. “It depends on how the device is being put in. If it’s emergent, there’s no time, but if we have been planning it for a long time, we do have a group of patients who have been identified to be very mature and who do want to talk to other patients, so we do that quite a bit. And we probably also need a pediatric support group,” he acknowledges.

Source

1. Czosek RJ, Bonney WJ, Cassedy A, et al. Impact of cardiac devices on the quality of life in pediatric patients. *Circ Arrhythm Electrophysiol* 2012; available at: <http://circep.ahajournals.org>.