

# Speaking to children and their families about congenital heart disease: Ushering in a new era of healthcare literacy

If we recall the children's hospitals of our own childhood, many of us will remember the Dickensian restrictions on parental visitation and the patronizing attitudes of the "doctor knows best" era. The landmark movies of James and Joyce Robertson such as "A Two-Year Old Goes to Hospital," made in London in the 1950s, focused a lens on the terrible psychological impact of hospitalization on the very young. A series of articles, beginning in the 1960s and 1970s highlighted the short-term impacts of hospitalization, for example, during cardiac catheterization, on the developing child.

More recent work has extended our knowledge to highlight the more long-term cognitive, social, and psychological impacts of chronic illness, including congenital heart disease, not only on the children themselves, but also on their extended family. Symptoms of posttraumatic stress can be readily discerned not only in many of our patients, but also in their siblings, parents, and grandparents. Clearly if we are to reduce the impact of these conditions on families, we must not only concentrate addressing the hemodynamic lesion, but also must adopt a wider view of their associated morbidity. As a result, one area engendering enormous and welcome recent interest relates to the determinants of neurodevelopmental outcome.

Some nice studies by Kendall and others around the turn of the century demonstrated that if one asks children what would help them to deal with their congenital heart disease, most will request information, both for them and for those around them. Paradoxically, very few young people have an adequate understanding of their condition. Similarly when parents are asked what would help them to deal better with their child's condition, they want more information about the condition and its impact on the child's life. They want to know how the condition will affect aspects of everyday living and not just a "medical" or "technical" explanation of the lesion. Sadly, important knowledge deficits exist among parents of children with heart disease regarding quite basic aspects of their child's diagnosis and treatment.

These and other articles herald a "call to arms" to the pediatric cardiology community to improve the health literacy of the families for whom we care. Improved health literacy is not just the provision of information for information's sake, but acknowledges, as suggested by the Institutes of Medicine, "the cumulative and consistent findings of a causal connection...between health literacy and health outcomes." Specifically within the field of congenital heart disease it has been shown that accurate understanding by the child of their cardiac condition results in reduced levels of distress, better compliance with treatment, and improved emotional state in the long term. Empowering

parents through knowledge, not only improves their ability to cope after their child's illness and reduces their symptoms of posttraumatic stress, but also improves behavioral symptoms in their child. Most intriguing of all might be the observations (although in small patient numbers) that early preparation of parents following the birth of a child with severe congenital heart disease not only reduces parental anxiety but also improves the mental scale of the Bayley-II in the infant.

It is easy for a parent to find information from thousands of web sites outlining the specific anatomical features of tetralogy of Fallot or tricuspid atresia. There are beautiful line drawings of the Norwood operation or the Nikaidoh procedure readily available for all. But what is more difficult, is for parents to find useful information about *what it is like* to have a child with tetralogy of Fallot or tricuspid atresia. What techniques might be helpful to the parent as they talk to older siblings about their newborn brother's congenital heart disease? What helpful tips can be provided to parents, to help them cope in the early days after their infant has been discharged after their Norwood operation, etc.? For the children themselves, what information might help them to prepare better for their cardiac surgery? How do they tell their school friends about their heart disease? And for the adolescents, what information might help them to broach the topic of their heart disease with girlfriends or boyfriends, for example?

One of the paradoxes is that the recognition of these important aspects of holistic care has occurred in a setting, which emphasizes "productivity," "patient throughput," and relative value units. It is unlikely that any of us will be able to provide the required information to children, their siblings and their carers during a normal clinic visit. Our efforts to enhance health literacy during our clinical consultations will have to be supplemented by accurate, entertaining, online resources that will be widely available to anyone who needs them. Thankfully, a number of centers are working toward developing these resources. As we watch their increasing development and adoption, we look forward to a new era of healthcare literacy.

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