Repaired congenital heart disease and our social milieu

Today, the management of congenital heart disease (CHD) involves surgical or nonsurgical correction at an appropriate time in the natural history as a standard of care in most parts of the world. In our country, surgical treatment for CHD became available in a limited way in the late 70s. However, the past two decades have witnessed a rapid expansion in the quantity and quality of care available for patients with CHD. Many hospitals across the country now offer neonatal and infant cardiac surgery, and many have the capability of managing complex congenital heart defects with a high degree of success.

This rapid progress has resulted in an ever-increasing population of children, adolescents, and young adults with "*repaired*" but not necessarily "*cured*" congenital heart defects. This group of patients includes those with palliated single ventricle, those having valved conduits, those with repaired or prosthetic valves and those with residual defects such as pulmonary regurgitation following repair of tetralogy of Fallot. Of necessity, these patients require periodic follow-up assessments and repeat interventions as and when indicated. In many instances, especially with single ventricle palliations, significant complications start surfacing in the second or third decades of life eventually resulting in a shortened lifespan.

We live in a society where family life generally revolves around the rearing and care and of children with the hopes of seeing them attain adulthood, get married, bear children, and then become caregivers in turn in later years. There are also hopes and desperate expectations of both academic laurels and a subsequent successful career. As the child with a "repaired" heart grows up the realization gradually dawns on many families that these wishes may never get fulfilled. The need to get their children married and "settled" to meet societal expectations becomes an overriding compulsion. This societal pressure is even more acute in the case of the girl child where the desire to get her married becomes an obsession as she approaches her twenties. However, our society is unfortunately very intolerant of imperfections in others, and a repaired heart or even a visible scar is a huge negative in the so-called "marriage market." Many women with operated CHD are therefore destined to remain single or accept unequal marriages. This often sets the stage for pathological depression. Interestingly, the male with operated CHD faces less discrimination in the "marriage market" but is, however, more likely to face hurdles in the "job market." With no available guidelines on cardiac disability, medical boards responsible for giving clearance for fitness for jobs are quick to reject such candidates even if they have no significant residual cardiac issues.

The other major source of mental stress for families is the financial burden of "so-called treated CHD." In a country, where state-supported healthcare is virtually nonexistent, most families have to pay out of pocket for congenital heart surgery, and costs of re-operations can become a huge financial drain if not totally unaffordable. This is more so if the use of a prosthetic valve or valved conduit is involved. Hospital readmissions for the management of long-term complications such as heart failure, arrhythmias, or endocarditis become a significant recurrent expenditure. Eventually, families are driven to either face financial ruin or take a difficult and painful decision to cease ongoing treatment. Family resources are often consumed at the expense of other siblings, generating resentment in them. Some young parents actually refrain from having more children either out of fear of having another child with CHD or to conserve their resources to look after "the one child with CHD" - however bleak the long-term outcome.

The psychological stress on parents caring for a child with complex CHD in our country is enormous. The possibility of a major cardiac complication occurring anytime or the knowledge that eventual lifespan will be curtailed hangs like a sword of Damocles. This is more pronounced in nuclear families that lack the social support of an extended family. Some parents, especially the mothers, carry a deep sense of guilt at having "produced" such a child. In other instances, insensitive family members may actually hold the mother guilty and trigger a marital break-up. There are instances where the affected children have turned against their parents, blaming them for their predicament. The "burn out" resulting from this chronic parental stress is evident from the fact that many of these parents look far older than their years when they come for their child's serial follow-ups!

As surgeons, cardiologists, and pediatricians we tend to focus on the task of "treating" the surgical or medical problem at hand. We may discuss surgical risks, long-term survival, and need for re-interventions in a

very matter of fact clinical manner without giving much thought to the overall impact our intervention may have both on child and the family dynamics. Our scientifically driven training drives us to recommend the best and latest treatment modality available, without giving much consideration to the social milieu that surrounds us. Most parents will follow the doctor's advice blindly and in full faith that it is what is best for the child. The need to do everything possible to "save" their child not only from death but also from suffering is a primal instinct. It is only later that the realization dawns that all they have managed to achieve is a postponement of that eventuality rather than a relief from it.

There is an urgent need that we as custodians of the well-being of children with CHD address these issues. These families need a lot of social and psychological support, and we need to set up mechanisms for the same. Social support and professional counseling for both the patient and the parents should become part of our follow-up protocols. The formation of parent support groups is a way forward and should be encouraged. We need to work on ways to sensitize society towards accepting these children as "individuals with capabilities" rather than look upon them as "handicapped." There is an urgent need to pressurize insurance companies to do justice to these individuals and provide them with insurance cover. We need to educate and sensitize government and corporate employers not to discriminate against them and encourage them to create avenues for gainful employment.

Above all, we need to relook at the way we counsel our families for intervention. "One dress does not fit all," and what may be acceptable and appropriate in an affluent developed country may not necessarily be the right approach in our country. Our counseling must provide a detailed but compassionate "down the road" outlook for the patient rather than only focusing on short-term outcomes. Our need for achieving a surgical success in a complex cardiac malformation should not override the need to very clearly outline the long-term consequences of such an intervention. It is a responsibility that we owe not only to the families but also to society. Whether or not to advise a Norwood procedure for a newborn with hypoplastic left heart syndrome born to parents with modest means and no financial support for the treatment, will remain a moral dilemma for us, but one that we have to give deep thought to and resolve in our own minds.

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