Contemporary use of ventricular assist devices in muscular dystrophy: a report from the ACTION learning collaborative

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Muscular dystrophy (MD) patients can suffer from significant cardiac disease with resultant major morbidity and mortality. The Advanced Cardiac Therapies Improving Outcomes Network (ACTION) sought to better characterize our previously described outcomes associated with VAD therapy across multiple centers. We examined outcomes of patients with MD and dilated cardiomyopathy implanted with a durable VAD at participating centers from 9/2012 to 1/2023. A total of 48 VADs were implanted in 33 patients across 15 sites. While four patients received a VAD from 2012 to 2017, a further 29 received a VAD from 2018 to 2023. The most common MD was a dystrophinopathy (Becker, Duchenne, intermediate or affected carrier), followed by Emery-Dreifuss, Limb Girdle and other MD. The median age at implant was 16.8 years (range 9.2-31.7). Seven (21%) patients were implanted as a bridge to transplant, 6 of whom survived to transplant. Of patients implanted as bridge to decision or destination therapy, 87% were alive at 1 year and 82% at 2 years. The overall frequencies of positive outcome (transplanted or alive on device) at 1 year and 2 years were 84% and 80%, respectively. Major complications included stroke (6%), sepsis (15%), tracheostomy (3%), and severe right heart failure requiring right-sided VAD (9%). Other common but not severe complications included other major infection (21%), bleeding (30%, although none required surgical intervention), and arrhythmias requiring cardioversion (15%). Longest follow-up in this cohort is now greater than 5 years on device. VADs are being increasingly utilized in the MD population and implantation can be successful, with similar complication rates to non-MD patients. Ongoing work in patient selection, assessing quality of life, and further surgical/medical optimization is needed.