Challenges of long-term VAD support, including non-transplant candidates

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Disclosures

None
VAD use in the pediatric patient

- Early 2000’s increase in VAD use in pediatric patients
  - Berlin Heart Excor IDE study
  - Early adoption of adult devices in pediatric patients
    - Thoratec PVAD/IVAD
    - HeartMate II
    - HeartWare
- Long-term VAD use more of an option now
- What is DT?
  - Destination therapy is when the VAD becomes the definitive treatment for long-term cardiac support in non-transplant candidates
Audience participation

• Does your institution use bridge to decision as an implantation option?
• At your institution, do you or have you had anyone labeled as DT?
• Do you have any VAD patients not listed for transplant?
• Do you think DT is viable option in pediatrics?
• Would you implant a VAD in a 16 yo as a DT patient?
• Would you implant a VAD in a 6 yo as a DT patient?
Who could be considered for DT or long-term VAD?

• No established set criteria exists for pediatric patients

• Possible diagnosis for DT:
  – Muscular Dystrophies (i.e. Duchenne)
  – Chemotoxicity-induced cardiomyopathy
  – Complex congenital heart disease with comorbidities
  – Retransplantation graft dysfunction and non-adherence issues
  – Cardiac dysfunction with neurologic impairment or uncertain neurodevelopmental outcomes

• Other contraindications to heart transplant to be considered for DT or long-term VAD:
  – Severe obesity
  – Cardiac cachexia
  – Cross-match incompatibility
  – Social contraindications
    • Psychiatric
    • Substance abuse
    • Lack of social support

Char et al., 2016
Vanderpluym et al., 2014
Can we as a pediatric heart failure/VAD community accept the idea of DT in a child?

OR

Are these patients long-term ‘bridge to decision’ patients?
Why would we consider this?

• Adult experience and ‘success’ with DT VAD
  – In the past decade, more than 1800 DT implants in adults

• Improvements in medical care leading to growing population of transplant-ineligible patients
  – Improve heart failure and symptoms
  – Improve quality of life
  – Prolong life

• Medical management versus surgical intervention for heart failure
  – Is there a point too far?

Chen et al., 2015
What are the potential risks/outcomes of VAD therapy?

- **Complications**
  - Stroke: ischemic and hemorrhagic
  - Driveline infection
  - Arrhythmias
  - Gastrointestinal bleeding
  - Device malfunction
  - Pump thrombosis/device exchange
  - Subtherapeutic anticoagulation

- **Outcomes of therapy:**
  - 9 centers, 12 patients; all HVAD patients
  - Indications:
    - DT=1
    - BTR=1
    - BTT=10
  - Average duration of support
    - Inpatient: 56 days (19-95)
    - Outpatient: 290 (42-790)
  - Mean readmission: 2.1 per patient
  - No mortality
  - Complications:
    - Driveline infection
    - Subtherapeutic INR
    - Alarming of the VAD

Schweiger et al., 2015
How do we decide to implant?

• Outlining & managing expectations
  – Goals of therapy
  – Rehospitalization reality
  – Complication reality
• Goals of the patient & family for VAD therapy
• Quality of life
  – Can only be defined and outlined by patient & family
• Informed consent
  – Evaluation of understanding from third party
• Do WE decide?
What if something happens?

- **BEFORE implant:**
  - Discuss criteria for elective VAD discontinuation for futile & non-futile situations
  - Advanced directive

- **During therapy:**
  - Continue to evaluate goals of use, QOL, and plan of care
  - Is the patient still where they or the caregiver want to be?

- **Proactive decision-making:**
  - For normal life events
    - prom, graduation, college
  - For worst case scenario
    - Catastrophic adverse event outside the hospital
    - Device deactivation
Decision-making with the pediatric patient

1. Consider the age of the patient
2. Autonomy/Adolescent decision-making
   - Consent (legally binding approval; age 18)
   - Assent (awareness & acknowledgement)
   - Informed refusal
   - Individual timing for appropriateness of decision making input
3. Device deactivation
   - Who decides?
   - When do you include/exclude the patient?
   - Altruistic surrogates for decision making
   - Impact to the care team
   - Ethical considerations and concerns

Hollander et al., 2016
Katz et al., 2016
How should we manage long-term pediatric VAD patients?

- Multidisciplinary team
  - Psychology, Pastoral Care, Provider team, Child Life, Social Work
  - Patient & Caregivers
  - Risk management
  - Ethics committee

- Palliative Care

- Community Outreach
  - School
  - Local EMS
  - Local ED
  - Primary Care Physician & Cardiologist
Long-Term Challenges

• Patient
  – Psychosocial issues (depression, anxiety, hopelessness, fear of the unknown)
  – Non-adherence
    • Medical & machine
    • Daily cares
  – Quality of life/goals of therapy
  – Autonomy and Safety
    • Can the patient be left alone?
    • At what age?
  – Social concerns
    • School or work transition
    • Adolescent risky behaviors
Long-Term Challenges

- Caregiver burden
  - Lack of support
  - Constant presence with patient
  - Implications to:
    - Work
    - Finances
    - Relationships/social support
  - Emotional burden

- Device
  - Lifespan
  - Device failure/malfunction
  - Maintenance
  - Equipment training
    - How many caregivers?
    - Re-education or validation?
Audience participation

- Do you think DT is viable option in pediatrics?
- Would you implant a VAD in a 16 yo as a DT patient?
- Would you implant a VAD in a 6 yo as a DT patient?
In the future

- Use of DT will continue to evolve, and increase in use
- The pediatric community needs:
  - Dedicated pediatric social media/online support network for patients
  - Continued collaboration and shared experience
  - Understanding ethical/legal implications for pediatric VAD patients
  - Set standards & expectations for long-term/DT pediatric VAD patient
  - More research
Thank you!

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Join the ICCAC VAD Pediatric Task Force Today!


