Control/Tracking Number: 22-RA-2565-ISHLT
Activity: Research Abstracts
Current Date/Time: 10/19/2021 1:17:28 PM

Outcomes After Initial Heart Failure Consultation In Fontan Patients

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Abstract:
Purpose Many individuals with a Fontan palliation will require advanced heart failure (HF) care during their lifetime. There are no standardized guidelines dictating the threshold for referral to a formal HF or heart transplant (HTx) service. Delays in referral can result in irreversible end-organ damage or clinical instability such that transplant or ventricular assist device (VAD) implant is too risky. Understanding current referral patterns and outcomes will help delineate recommendations on timing for initiation of HF/HTx care.
Methods Centers participating in the ACTION collaborative were invited to share data on characteristics of Fontan patients (any age) at the time of an initial consultation with a HF/HTx team; a follow-up survey was sent at 30 days to determine outcome after initial consultation. The primary outcome was "late referral", defined as death or declined for HTx and/or VAD due to too sick; a secondary outcome of "care escalation" was defined as VAD implant, inotrope initiation or HTx listing. Characteristics at time of initial consultation were examined.
Results From 7/2019 to 7/2021, 13 ACTION centers contributed data on 60 Fontan patients seen for an initial HF/HTx consultation. Table 1 shows the characteristics at time of initial consultation; 50% were inpatient consults and 33% of inpatients were already on inotropic support at time of consult. At 30 days, 12% were found to be late referrals (too sick for HTx/VAD = 6, died =1), and 38% had care escalation (initiated inotrope = 6 and/or VAD implant = 4 and/or HTx list = 16). Initial consult ≤ 1 year post-Fontan was associated with late referral (OR 8.8, 95% CI 1.6-47.7, p=0.012), while inpatient at initial consult was associated with late referral or care escalation (OR 3.1, 95% CI 1.1-8.8, p=0.040).
Conclusion Over a third of Fontan patients seen for an initial consultation by a HF/HTx team have care escalation within 30 days, with 12% referred too late. Earlier referral for advanced HF care in Fontan patients, especially before hospitalization, is needed.

Table 1. Patient characteristics at time of heart failure/transplant consultation (n=60)

	All (n=60)	Late referral (n=7)	Not late (n=53)	p-value
Age at consult (years)	13.3 (7.3, 15.5)	12.5 (5.5, 15.5)	13.5 (7.5, 16.5)	0.534
Time from Fontan (years)	8.0 (2.5, 12.5)	1 (0.5, 12)	8.5 (4, 13.5)	0.089
≤1 year from Fontan	11 (18)	4 (57)	7 (13)	**0.005**
Weight (kg)	42 (21, 57)	29 (16, 45)	44 (23, 58)	0.145
Height (cm)	142 (117, 163)	122 (96, 148)	143 (118, 163)	0.275
Male	38 (63)	3 (43)	35 (66)	0.475
Inpatient	30 (50)	4 (57)	26 (48)	0.232
≥ Moderate systolic dysfunction[1]	19 (32)	3 (43)	16 (31)	0.498
≥ Moderate AVVR[1]	22 (37)	4 (57)	18 (35)	0.247
On inotropes	11 (18)	1 (14)	10 (19)	0.768
Exercise intolerance	43 (72)	6 (86)	37 (71)	0.416
NYHA Class 3-4	22 (37)	5 (71)	17 (32)	**0.042**
Pacemaker/ICD	13 (22)	0 (0)	13 (25)	0.139
Chronic/recurrent ascites	16 (27)	2 (29)	14 (26)	0.903
Chronic/recurrent pleural effusions	12 (20)	3 (43)	9 (17)	0.108
Protein-losing enteropathy	20 (33)	0 (0)	20 (38)	**0.047**
Plastic bronchitis	3 (5)	0 (0)	3 (6)	0.510
Liver fibrosis[2]	21 (36)	1 (17)	20 (38)	0.293
Liver dysfunction[2]	5 (8)	0 (0)	5 (9)	0.432
Lab data				
Total bilirubin (mg/dL)	0.8 (0.6, 1.3)	1.7 (1.1, 2.7)	0.8 (0.5, 1.1)	**0.009**
Creatinine (mg/dL)	0.54 (0.45, 0.77)	0.75 (0.52, 1.60)	0.54 (0.45, 0.70)	0.138
Cystatin C (mg/L)	0.91 (0.80, 1.37)	1.77 (1.52, 2.02)	0.89 (0.79, 1.23)	0.054
BUN (mg/dL)	14 (11, 18)	20 (13, 21)	14 (11, 18)	0.175
Cath data (last 2 years)				
Fontan pressure (mmHg)	15 (14, 19)	17 (15, 26)	15 (14, 19)	0.346
End-diastolic pressure (mmHg)	10 (8, 13)	7 (4, 9)	11 (8, 13)	0.125
Cardiac index (L/min/m^2)	2.9 (2.5, 3.4)	2.8 (2.5, 3.7)	3.0 (2.5, 3.4)	0.714
Systemic O2 saturation (%)	87 (81, 92)	85 (77, 95)	88 (82, 92)	0.973
In the past year…				
Diuretic added	25 (43)	2 (33)	23 (44)	0.610
Hospitalized	12 (20)	2 (29)	10 (19)	0.564
Arrhythmias	14 (24)	1 (14)	13 (25)	0.532

Data are presented as N (%) or median (25th, 75th percentiles)
Abbreviations: AVVR, atrioventricular valve regurgitation; NYHA, New York Heart Association; BUN, blood urea nitrogen
[1] Systolic function and AV valve regurgitation from echo (n=50), MRI (n=2) or cath (n=5)
[2] Liver fibrosis as described on any imaging study; synthetic liver dysfunction includes elevated INR in the absence of anticoagulation with warfarin, abnormally low platelets, abnormally low pre-albumin and other markers

Author Disclosure Information:

S. Chen: None. **M.F. Shezad:** None. **A. Lorts:** Consultant; Current/Ongoing - Payment Made to Me; Abbott, Berlin Heart, Medtronic. **A.D. McCormick:** None. **C.Y. Mao:** None. **K. Simpson:** None. **M.J. O'Connor:** None. **A. Barnes:** None. **A. Lubert:** None. **C. Castleberry:** None. **J. Schmidt:** None. **A. Joong:** None. **D.W. Bearl:** None. **A.K. Lal:** None. **D. Mokshagundam:** None. **J. Conway:** None. **A. Cedars:** None. **K. Schumacher:** None.

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