

CARDIOLOGY
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Heart to Heart: Navigating Challenges in Adolescent Transplant

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HOPE. HEAL. LEARN.



CASE STUDY

- 24 year old with a history of HLHS
- Norwood as 5 day old
- Hemi-Fontan at 6 months old
- Fenestrated lateral tunneled Fontan at 20 months old
- Developed PLE in 2009-2010
- Referred to transplant program in 2014

CASE STUDY

- Presented to transplant team for ongoing PLE symptoms
- Facial edema, periorbital edema, very distended abdomen with firm liver (noted as low as 9cm below RCM)
- On diuril BID, Lasix BID, metolazone twice weekly. High dose spironolactone
- Albumin and Lasix infusions every 2 weeks for many years
- Developmental delays

CASE STUDY

- High risk candidate
- Listed for transplant as a status 1B in 2014, minimal social concerns
- Made inactive on the transplant list in January 2015 due to suicidal ideations and nonadherence, followed by medical complications
- Made active as 1B in June 2016

POST-TRANSPLANT

- Underwent transplant on 8/10/2019
- Compliant with early visits, meds, clinically doing well
- Documentation of knowing all of her medication names and doses
- Reasonable medication list
- Continued in rehab and began receiving botox injections



POST-TRANSPLANT

- Early 2022 – began having poor med adherence as suicide attempt, confirmed with undetectable levels of immune suppression
- Also with concerns for PID and STI, recent unprotected sexual activity
- Discharged after 5 days, recommended close psych follow up
- However, problems continued....

POST-TRANSPLANT NON COMPLIANCE IN THE LITERATURE

- Studies finding that non-adherence rates in adolescents vary, may be as high as 65-75%
- Of all age groups, adolescents hold the highest rates of nonadherence however stress and nonadherence can occur in any age
- Period of transition to adult care is a high risk for nonadherence
- There are serious consequences of nonadherence post-transplant, one study finding in patients with more than 2 reported episodes of nonadherence and rejection a 56% mortality rate in 2 years
- Strong associations between psychosocial variables (child responsible for medication, psychiatric comorbidities) and nonadherence
- “Interventions aimed at promoting medication adherence in this population are urgently needed”

WHAT LEADS TO NONADHERENCE?

- Forgetfulness
- Inadequate regimen knowledge
- Difficulty with ingestion (number of meds, size, taste)
- Barriers to medication access
- Depression/anxiety, substance abuse, trauma
- Bullying
- Lack of parental involvement and monitoring, poor social support
- Disease frustration

WHAT CAN WE DO?

- Motivational interviewing & education of risks of nonadherence
- For forgetful patients, using reminders, pill boxes, blister packs
- Dosage simplification as appropriate
- Assess barriers to taking pills
- Using technology-based interventions is better appreciated by adolescents
- Encouraging enhanced parental monitoring and supervision
- Support groups for adolescent transplant patients
- Transition to adult care: slowly and gradually to promote comfort with new team, frequent monitoring in this period
- Psychosocial support?



TABLE 1. Medication reminder smartphone applications

App name	Compatible	Cost	Location
My Med Schedule	Android, iOS 7.0 or later	Free	Google Play Store, Apple App Store
MediSafe Meds and Pill Reminder	Android, iOS 8.0 or later	Free	Google Play Store, Apple App Store
Medi-Prompt	iOS 6.0 or later	\$3.99	Apple App Store
Pill Reminder—All in One	iOS 6.0 or later	Free	Apple App Store
My Pillbox	Android	Free	Google Play Store
MedCoach	iOS 6.0 or later	Free	Apple App Store
Transplant Hero	iOS 8.0 or later	Free	Apple App Store
Easy Pill	iOS 7.0 or later	\$2.99	Apple App Store

Note. iOS, Apple (Cupertino, CA) operating system.

Applications created directly for teens with transplants (i.e., Teen Pocket PATH) are not yet available (Shellimer, Dew, Mazariegos, & DeVito Dabbs, 2016).

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