



E529

JACC March 12, 2013

Volume 61, Issue 10



Congenital Cardiology Solutions

UTILIZATION OF AN ELECTRONIC PERSONAL HEALTH RECORD BY ADOLESCENTS AND ADULTS WITH CONGENITAL HEART DISEASE

Poster Contributions

Poster Sessions, Expo North

Sunday, March 10, 2013, 3:45 p.m.-4:30 p.m.

Session Title: Congenital Cardiology Solutions: Pot Pourri

Abstract Category: 12. Congenital Cardiology Solutions: Adult

Presentation Number: 1248-134

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Background: We have previously reported on development and implementation of www.followmyheart.org (FMH), a condition specific electronic personal health record (PHR) for patients with congenital heart disease (CHD). We now aim to describe patient utilization of FMH during the first 12 months of enrollment. We hypothesize that patient age and disease severity may correlate with frequency of PHR use.

Methods: All patients >15 years (y) of age seen in the Transition Clinic and Washington Adult Congenital Heart of the were offered enrollment in FMH from February 2011- October 2012. Demographic information (age, ethnicity, gender, educational level) and severity of disease were recorded. Individual patient log ins to FMH were tracked by an imbedded site function. Correlation analysis examined the relationship between demographic sub-groups and disease severity with PHR use.

Results: From February 2011 - October 2012 127 CHD patients > 15 y old registered for FMH; 81 participated in the study. Disease ranged from mild, moderate, to severe with mild patients being significantly younger than those with moderate or severe disease (mean age (SD): 24.0 y (8.5), 29.1 y (10.8), 28.3 y (8.8), $p=0.04$). Three patients died and 1 withdrew during the study. Among the 77 remaining patients, there were 523 FMH log ins (range 0-71, mean frequency (SD) of 6.8 (11.2) times per patient per year). Mean frequency of use varied with age (<18 y - 3.0 (4.9), 18 - 21 y - 4.7 (10.6), >21y 7.9 (11.8), $p=0.009$). Older age category (>21 y) correlated with increased FMH use ($R=0.34$, $p=0.002$) while ethnicity, gender, educational level, and disease severity did not. There was a four-fold increase in rate of FMH use among women who were pregnant (all>21 y) during the study compared to the group as a whole. Patients reported liking the ability to access, share, and print their medical and surgical information and found it most useful in emergency situations.

Conclusions: PHR use among CHD patients was frequent but highly variable. Increased FMH use correlated with older age category but not with severity of disease and often related to acute intercurrent illness or pregnancy.