

Building a Data Registry to Evaluate the Effectiveness of Multi-disciplinary Management of Renal Disease During Pregnancy at the Pregnancy Heart and Kidney Center (PHKC).

William Rallya
USF MCOM- LVHN Campus, William.Rallya@lvhn.org

Follow this and additional works at: <https://scholarlyworks.lvhn.org/select-program>



Part of the [Medical Education Commons](#)

Let us know how access to this document benefits you

Published In/Presented At

Rallya, W. (2017, March). *Building a Data Registry to Evaluate the Effectiveness of Multi-disciplinary Management of Renal Disease During Pregnancy at the Pregnancy Heart and Kidney Center (PHKC)*. Poster Presented at: 2017 SELECT Capstone Posters and Presentations Day. Kasych Family Pavilion, Lehigh Valley Health Network, Allentown, PA.

This Poster is brought to you for free and open access by LVHN Scholarly Works. It has been accepted for inclusion in LVHN Scholarly Works by an authorized administrator. For more information, please contact LibraryServices@lvhn.org.

Building a Data Registry to Evaluate the Effectiveness of Multi-disciplinary Management of Renal Disease During Pregnancy at the Pregnancy Heart and Kidney Center (PHKC)

William Rallya

Lehigh Valley Health Network, Allentown, PA

Introduction/Background

Kidney disease during pregnancy can have devastating effects on both maternal and fetal outcomes and still remains among the greatest threats to successful pregnancy. Maternal outcomes include gestational hypertension, preeclampsia, eclampsia, long-term worsening of Chronic Kidney Disease (CKD), and mortality. Fetal outcomes include prematurity, intrauterine growth restriction, preterm delivery, low birth weight, stillbirth, and mortality. As such, it is currently recommended that pregnant women with CKD begin care as early as possible in pregnancy with a multi-disciplinary team consisting of specialists in obstetrics, nephrology, maternal fetal medicine, urology, and neonatology. However, while this is the current recommendation, little data is available demonstrating whether or not this approach provides any benefit to the mother or fetus.

The Department of Maternal Fetal Medicine, the Department of Nephrology, and the Department of Cardiology at the Lehigh Valley Health Network (LVHN) established the Pregnancy Heart and Kidney Center (PHKC) in 2012 to provide collaborative multi-disciplinary clinical care to pregnant women with heart and kidney disease. As such, the PHKC is interested in investigating whether or not this multi-disciplinary approach to the management of CKD in pregnancy is improving maternal and fetal outcomes. Our project begins the investigation with the building of an electronic data collection system as well as with early data collection and entry so to provide the foundation for future investigation into maternal and fetal outcomes. This effort establishes an academic collaboration, built upon our clinical collaboration, on the PHKC program effectiveness between the Division of Nephrology with its Fellowship Program and the Division of Maternal Fetal Medicine with the OB/GYN Department Residency Program.

Problem Statement

We endeavored to build an electronic data registry using the REDCap system and to begin early data entry so to provide the foundation for future investigation into maternal and fetal outcomes for those pregnancies complicated by maternal CKD and cared for at the PHKC.

Methods

Our project consists of building a data registry of retrospective patient information from the medical records of those cared for at the PHKC from 2012 to December 2016 with hopes of establishing a database capable of collecting data prospectively as the program continues. To do this we are using REDCap, “a mature, secure web application for building and managing online surveys and databases” developed by Vanderbilt University and “now supported by a global consortium of non-profit organizations.”¹ Each consortium site (i.e., LVHN) runs its own independent REDCap system, which is both HIPAA compliant and IRB approved for research purposes. The project was approved for expedited IRB review and approved as a data registry.

References:

1. REDCAP. Research Electronic Data Capture. Powered by Vanderbilt University. 2017. <<https://projectredcap.org/about/>>

Results

The PHKC registry is currently gathering retrospective data for each patient that has been cared for at the PHKC since its beginning in 2012 until December 2016. The data being gathered includes demographic information, past medical history, medications, laboratory data, physical exam data, signs and symptoms reported by the patient, and reasons for referral to the PHKC. Data collection begin at a patient's first visit with the PHKC and includes each follow-up visit, any related hospitalizations during the pregnancy, and labor and delivery.



Conclusions and Future Implications

The REDCap based PHKC Registry is a dynamic data collection system that will allow for greater review and analysis. As such, future analysis of the retrospective data currently collected and the prospective data to come will hopefully illuminate the benefits of this collaborative multi-disciplinary approach to caring for pregnant women with CKD.



© 2017 Lehigh Valley Health Network