Endocrine Fellows Foundation Grant Final Report

Investigator: Karishma Datye, MD

Title of Project: Assessing Barriers to Adherence in Adolescents with Type 1 Diabetes (T1D).

Project Period: April 2015-April 2016

Final Report:

Specific Aim 1: To define age-specific barriers to adherence in adolescents age 11-21 with T1D using validated measures and to examine associations between barriers and glycemic control.

The purpose of this Aim was to define barriers to adherence in patients with T1D who were in 3 different developmental stages (ages 11-13, 14-16, and 17-21). Each participant completed validated measures including the Self-Care Inventory (SCI), the Problem Recognition in Illness Self-Management (PRISM) inventory, and a demographic inventory. Parents of participants age 17 and under also completed parent versions of these inventories. The recruitment goal for this Aim (60 participants) was achieved. In each age category 20 participants were recruited. After completing Aim 1 of this project, my mentors and I analyzed the inventory data assessing barriers to adherence. In the 17-21 age group, barriers to adherence included understanding/organizing care, and pain and bother related to the diabetes regimen. These barriers guided the creation of specific focus group questions asked in Aim 2 (see below). These inventories were also completed by participants in Aim 2, and combined analyses from the inventories in Aim 1 and Aim 2 are underway. Analyses will include bivariate correlations to determine the associations between adherence, barriers, and glycemic control.

After completing Aim 1 of this study, I was fortunate to partner with another study focusing on accurate measures of adherence to therapy in youth with type 1 diabetes. After combining our Self-Care Inventory, glucometer download, and Hgb A1c data we found that adolescents’ self-report of adherence was correlated with objective measures of glycemic control (hemoglobin A1c) suggesting that adolescent self-report is an important assessment of adherence to therapy. This is a novel finding as typically adherence to therapy is measured using glucometer downloads or parent report, and these data suggest that including the patient perspective is critical in understanding how a patient adheres to his or her treatment plan. These findings were presented (oral presentation) at the American Diabetes Association 76th Scientific Sessions 2016 (see Scholarship During Funding Period), and a manuscript describing these data is currently being prepared.

Specific Aim 2: To describe modifiable barriers and facilitators to adherence through focus groups with adolescents with T1D in good and poor control.

The purpose of Aim 2 was to explore facilitators of adherence and describe modifiable barriers to adherence using focus groups of adolescents with T1D in good and poor glycemic control. The focus group protocol was created in conjunction/consultation with the Qualitative Core, a unique resource at Vanderbilt with experts in qualitative methods. After discussion with the
Qualitative Core, a focus group was conducted in the 17-21 age group. The experts in the Core felt that it would be difficult to engage participants in the 11-13 and 14-16 age groups; therefore this Aim was completed only in the 17-21 year old age range. Inventories assessing barriers to adherence completed in the 17-21 age group (Aim 1) guided creation of focus group questions. A focus group in the 17-21 year old age group led to robust discussion of barriers and facilitators to adherence in type 1 diabetes. The Qualitative Core is currently transcribing and coding the focus group session to determine key barriers and facilitators that emerged during the focus group. Once this initial analysis is complete, I will review key barriers/facilitators that emerged, and will meet with the Qualitative Core to determine if additional focus groups are necessary in this age group to reach concept saturation.

I plan to publish a mixed methods manuscript describing data from Aims 1 and 2 once analyses from these Aims are complete.

Career Goals:

Early in my first year of pediatric endocrinology fellowship I developed an interest in adherence to therapy. My interest in patient adherence stemmed from interacting with my patients with type 1 diabetes. I realized that despite amazing advances in insulin development and delivery (e.g. insulin pumps and continuous glucose monitoring), poor adherence to therapy was the main driver of poor glycemic control, and without optimal adherence no therapy would be successful. Therefore, for the last 3 years I have investigated adherence to therapy in adolescents with type 1 diabetes.

In my second year of fellowship I was very fortunate to receive the Endocrine Fellows Foundation Research Grant in Diabetes to pursue my research project examining adherence to therapy in youth with type 1 diabetes. Under the excellent mentorship of my mentors Dr. William Russell and Dr. Sarah Jaser and my scholarship oversight committee I developed a research plan to assess adherence to therapy in youth with type 1 diabetes. My ultimate goal in identifying these barriers to adherence is the creation and implementation of clinic-based, provider-led interventions to address and minimize these barriers, thereby improving adherence and glycemic control.

This research project has provided me the opportunity to engage with diabetes experts on a national level, and transition my research to national cohorts of youth with type 1 diabetes. In Aim 1 of my research project, I found that participants reported difficulties in remembering to give their meal insulin, which ultimately resulted in missed meal insulin. I also noted significant variation in how participants give meal insulin, ranging from before meal, during, or after the meal. To further investigate timing of meal insulin in patients with type 1 diabetes, and whether specific timing of meal doses was associated with missed meal doses, I queried the T1D Exchange Clinic Registry, a national database with over 25,000 participants. I worked with members of the T1D Exchange (composed of international experts in pediatric diabetes) to analyze these data, and together we found that giving insulin during or after a meal was associated with missed insulin doses and ultimately worse glycemic control. This project provided me the opportunity to engage nationally with leaders in type 1 diabetes, to present a
barrier to adherence to therapy in type 1 diabetes in a national forum (see below), and discuss provider driven interventions to mitigate this barrier.

In the coming year I will expand my training to include an advanced academy for Quality Improvement which will focus on improving the quality of care of my patients, and ensuring that as providers we are adhering to national metrics and clinical guidelines to provide the best care to our patients. I will also continue to expand my research program as I begin a project to improve access and delivery of diabetes care to our most vulnerable youth with diabetes. Looking forward I believe my pediatric endocrinology fellowship and the Endocrine Fellows Foundation Research Grant in Diabetes has provided me with the background and skills I need to improve adherence to therapy in youth with diabetes and endocrinologic diseases. The unique training I have received in fellowship has positioned me to be a leader in the field of adherence in pediatric endocrinology.

Scholarship During Funding Period:

Presentations:


Publications:

3. Patel NJ, Datye KA, Jaser SS. Importance of Patient-Provider Communication to Adherence in Adolescents with Type 1 Diabetes. Under Review.