PI: Caroline Schulmeister, MD
Position: Fellow/Non ACGME Fellow at University of California, San Francisco
Project: Telemedicine in Racial and Ethnic Minority Youth with Diabetes: Addressing the Gap in Care

ISPAD-JDRF Research Fellowship Award Progress Report

Telemedicine in Racial and Ethnic Minority Youth with Diabetes: Addressing the Gap in Care

Problem Statement:

Racial and ethnic minority youth with type 1 and type 2 diabetes develop serious, debilitating disease-related complications earlier in life and have mortality rates that are twice that of non-Hispanic White youth.[1] Compared to non-Hispanic White youth, Black and Latinx youth with type 1 and type 2 diabetes experience less optimal glycemic control, as measured by higher hemoglobin A1c (A1c),[2,3] which is known to contribute to the development of diabetic retinopathy, cardiovascular disease, nephropathy, neuropathy, and stroke.[4] In addition, diabetes with poor glycemic control is a known risk factor for higher morbidity and mortality in those infected with COVID-19,[5] a virus that has disproportionally affected racial and ethnic minorities with greater rates of hospitalization and mortality compared to non-Hispanic Whites.[6,7] There are likely multiple psychosocial factors contributing to the disparity seen in glycemic control in racial and ethnic minority youth with diabetes including family dynamics, depression, and disparities in health literacy.[8,9,10]

Pediatric patients with at least quarterly diabetes visits with their clinician have been shown to have lower A1c levels compared to those seen only 1-2 times per year.[11] Racial-ethnic minority youth and those from families with lower annual income are more likely to miss appointments with their diabetes providers, impacting short and long term outcomes. [12,13,14] Irregular clinic attendance is associated with increased episodes of diabetic ketoacidosis (DKA) and increased incidence of retinopathy.[14] Missed appointments further contribute to disparities in clinical outcomes by creating obstacles to regular communication and opportunities for continued diabetes-related education from the clinical care team.[15]

Telemedicine, the delivery of clinical care via remote video-conferencing, has been shown to be an effective means of providing care to individuals with diabetes, with improved cost-effectiveness and patient satisfaction.[16,17] Diabetes care is well-suited for telemedicine since use of devices such as insulin pumps and continuous glucose monitoring (CGM) have become more frequent, and device data can be uploaded remotely by the patient at home for a provider to view electronically during telemedicine visits.[18] Telemedicine has been incorporated into many pediatric endocrinology practices as a way to facilitate regular attendance at diabetes clinic visits by providing easier access to the diabetes team and a reduction in travel time and school and work absences.

Despite the promise of the use of telemedicine, barriers to participation exist in racial and ethnic minority populations. Prior studies have shown that urban ethnic minorities have been reluctant to pursue telemedicine due to distrust and concerns about confidentiality.[19] Other obstacles may exist related to employment, poor access to technology or a reliable internet connection, and poor electronic literacy.[20] These parameters can be especially lacking in populations with an overall lower socioeconomic background. The current COVID-19 pandemic has further exacerbated inequities in access to care for racial and ethnic minority youth with diabetes as many institutions rapidly shifted away from in-person visits in favor of telemedicine visits to reduce virus exposure risk. In fact, a lower proportion of ethnic minority patients have accessed telemedicine during the COVID-19 pandemic.[21]

University of California, San Francisco (UCSF) Benioff Children's Hospitals (BCH) has two main campuses in San Francisco (West Bay) and Oakland (East Bay). At BCH, telemedicine visits made up 68% of all diabetes visits by April 1, 2020. Between April and July 2020, the West Bay campus, which has a larger non-Hispanic White patient population, had 23% more visits scheduled compared to the East Bay campus, despite the fact that the East Bay campus has a 52% greater patient population size. Of the East Bay patients who "no showed" to their clinic visits since the start of the pandemic, 53% identified as Latinx, 29% as Black, and 6% as non-Hispanic White, showing disproportionately higher percentages of racial-ethnic minorities who did not attend visits at a clinic which is 35% Latinx, 12% Black, and 29% non-Hispanic White. Similarly, in the West Bay, patients who "no showed" to clinic visits during the pandemic were 30% Latinx, 16% Black, and 23% non-Hispanic White, in a clinic population which is 22% Latinx, 5% Black, and 54% non-Hispanic White. This disparity in visit attendance is an example of how the current COVID-19 pandemic has further exacerbated barriers to care for racial-ethnic minority populations.

Even beyond the pandemic, telemedicine will continue to be a way to effectively supplement in-person visits for children and families living with diabetes. It is paramount for pediatric endocrinology practices to better understand if and why a telemedicine utilization gap exists amongst underserved communities and to develop strategies to address this disparity. Our goal is to 1) characterize the current state, the barriers, and the facilitators of telehealth usage among racial-ethnic minority youth with diabetes in an urban, multidisciplinary pediatric diabetes center and 2) develop culturally sensitive strategies to enhance access to telemedicine care among vulnerable populations. This will ultimately lead to improved overall visit attendance, relationships with healthcare providers, and more optimal clinical and psychosocial outcomes in racial-ethnic minority youth living with diabetes.

Goals:

Our goal is to reduce disparities in access to telemedicine in racial-ethnic minority youth with diabetes with the following specific aims:

1. Involve community and provider stakeholders to characterize the current state, the barriers, and the facilitators of telehealth usage among racial-ethnic minority youth with diabetes in an urban, multidisciplinary pediatric diabetes center.
2. Use quality improvement strategies to implement small scale rapid cycle changes to address the barriers to care, evaluate their effectiveness, and develop a protocol for delivering telemedicine to racial-ethnic minority youth.

Project Design:

We will use a mixed methods approach to develop and implement a protocol to address disparities in access to telemedicine in racial-ethnic minority youth with diabetes receiving care at BCH. BCH serves approximately 1,000 children living with diabetes at the West Bay and East Bay campuses as well as multiple satellite campuses in the San Francisco Bay Area. We have a multidisciplinary clinic model which includes diabetes providers (Medical Doctors and Nurse Practitioners), Certified Diabetes Educators, Registered Dietitians, and social workers. Our sites are California Children's Services (CCS) credentialed centers. The initiative will be divided into two phases; an assessment phase and a quality improvement phase.

Aim 1: Assessment Phase: Involve community and provider stakeholders to characterize the current state, the barriers, and the facilitators of telehealth usage among racial-ethnic minority youth with diabetes in an urban, multidisciplinary pediatric diabetes center.

We will create Patient and Provider Advisory Boards to help assess the current state of telemedicine care. The Patient Advisory Board will consist of pediatric patients and family members living with diabetes. We will select members based on their identified gender, race, ethnicity, diabetes control, and frequency of both in-person and telehealth visits. We will conduct multiple focus groups with the Patient Advisory Board throughout the project period to discuss patient and family experiences, preferences, and priorities for receiving telemedicine care. This will include describing positive and negative aspects of both past telehealth experiences as well as in-person visits. We recognize that a provider's view of how telemedicine can supplement care may not align with perceptions in the community, and we will seek to understand preferences for if and how telemedicine can supplement or replace quarterly in-person visits. It will be important to understand possible perceived barriers to using telemedicine and how to best approach these within the community. We will also discuss the potential issues of digital literacy and technology access to reliable internet with a phone/computer. The Patient Advisory Board will be crucial to help determine the key intervention areas to improve telemedicine access and utilization during the Quality Improvement Phase.

The Provider Advisory Board will consist of diabetes care providers, diabetes nurse educators, social workers, psychologists, dieticians, and administrative staff from our institution. The Provider Advisory Board will help us understand how telehealth visits are scheduled and how patients/families are prepared for the visits. We will assess the perceptions of clinic staff regarding the barriers to telemedicine, while also learning from stories of families who were and were not able to effectively transition to telemedicine.

Qualitative content analysis of focus group interview data will be performed using grounded theory techniques. [22,23,24,25,26] We will engage in memoing (recording reflective notes) during open coding to capture out perspectives, ideas, and decisions as researchers. Themes and patterns will be identified from open codes and will be compared between different focus groups. The findings will provide a description of concepts and reflect participants' and researchers' perspectives. We will use Atlas.ti software to assist in this analysis.

Aim 2: Quality Improvement Phase: Use quality improvement strategies to implement small scale rapid cycle changes to address the barriers to care and evaluate their effectiveness.

We will use the Model for Improvement framework to conduct multiple Plan-Do-Study-Act (PDSA) cycles to develop interventions aimed at improvement, test these interventions, and redesign as necessary. The PDSA cycle is a pragmatic scientific method for testing changes in a complex system such as healthcare, and mirrors scientific experimental model of forming a hypothesis, collecting data, testing the hypothesis, and interpreting the results.[27] This approach promotes the use of a small scale, iterative approach to test interventions with rapid assessment and adaptation of changes according to feedback.

We will engage the Patient and Provider Advisory Boards at a minimum of once every three months throughout the PDSA process to help evaluate intervention efficacy and address challenges encountered with intervention implementation. We will evaluate improvement in each cycle using run charts focusing on the percentage of racial-ethnic minority youth with diabetes with scheduled telehealth visits, converting in-person visits to telehealth visits and vice versa, and telehealth visits attended compared to no-show. The production of a Diabetes Registry at our center is already underway and will allow us to easily track visit and will assist in assessing the progress of this project. Anticipated interventions include improved patient instruction/education materials regarding their telehealth visits and pre-visit diabetes data uploads, formal assessments of individual patient barriers prior to a scheduled telehealth visit such as lack of wireless connectivity or phone/computer, telehealth patient navigators to assist with patient barriers that may exist and troubleshoot challenges that may occur during a scheduled visit, and effective patient reminders regarding upcoming appointments. We will use the successful interventions to design a clinical protocol for providing telemedicine care to racial-ethnic minority youth. This protocol will also be available in patient-preferred languages and we will develop any necessary targeted interventions to promote success with the diverse groups of racial-ethnic minority youth we serve.

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Progress to Date:

Attainment of an IRB

After notification of the award in December, the PI applied for IRB approval. It was approved for both the San Francisco and Oakland sites in March, 2021.

Assembled Provider Advisory Board and Preliminary Analysis

After IRB approval, a Provider Advisory Board was created which consists of three providers (one MD, two NPs) and one CDE. The Advisory Board was a mix of individuals who work at both the San Francisco and the Oakland sites. Individual interviews were conducted by the PI with each board member over the Spring and early Summer 2021.

In addition, ancillary staff such as office associates and administrators at both the San Francisco and the Oakland locations were interviewed by the PI. A Process Map was created to describe the systems in place for providing telemedicine diabetes care at both BCH locations.

Provider Advisory Board interviews were coded for recurring themes. A Key Driver Diagram (Figure 1) was created to organize themes noted during both the Board interviews and ancillary staff interviews. Our study aims were broken down into primary and secondary drivers which were included in the Driver Diagram.

Adjustment in Patient Feedback Strategy

There have been multiple attempts to develop a Patient Advisory Board that mirrored the Provider Advisory Board. We are targeting racial-ethnic minority participants who have a history of missed telemedicine appointments or are reluctant to make telemedicine appointments. Unfortunately, there were few recommended participants from providers, and it has been challenging to recruit participants from our target population. This is likely due to multiple factors including the ongoing pandemic with limited in person interactions and need to conduct interviews remotely in a population already less likely to utilize telemedicine, potential communication barriers, and other stressors such as time. As a result of this, we have amended the IRB to allow for the PI to review provider schedules and identify potential participants to recruit. Additional methods are also being considered to obtain family input such as administering surveys to decrease the time commitment needed for participation.

Created Quantitative Data Collection Processes and Initial Data Analysis

The PI worked with an Epic analyst to create an algorithm for data extraction. This algorithm was analyzed and reviewed for accuracy and completion. Variables include all appointments scheduled with the type of appointment, if it was completed/cancelled/no-showed, appointment location, patient reported race/ethnicity, age, diagnosis, HbA1c, previous HbA1c and last appointment date. A preliminary analysis of data has been completed to uncover trends of telemedicine use within different patient populations.

Future Work

We plan to continue to work on obtaining patient feedback for analysis. In addition, we will continue to work on data collection and data analysis. We anticipate future publication in a peer-reviewed journal.

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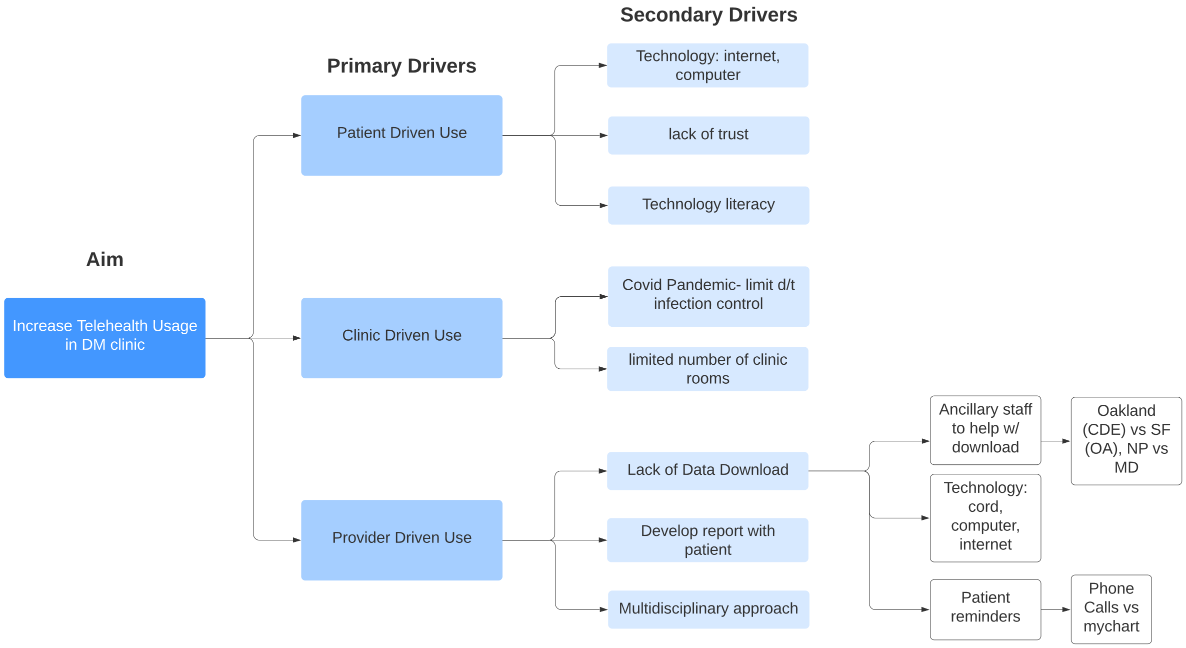
Figure 1: Key Driver Diagram



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