CASE STUDY

Medical College of Wisconsin Leverages the TriNetX Platform to Win Grant Funding to Study Outcomes and Risk Factors for Sickle Cell Disease Patients with COVID-19

INVESTIGATOR

Dr. Ashima Singh, Assistant Professor, Department of Pediatric Hematology Oncology BMT Division

CHALLENGE

Accessing a large data set of patients with Sickle Cell Disease to study the impact of COVID-19 on embolism rates.

SOLUTION

Dr. Singh leveraged the TriNetX platform to obtain real-world data to validate study feasibility and earn a grant from the MCW Children's Research Institute.

RESULTS

Thanks to the TriNetX platform, Dr. Singh and team were awarded a pilot grant that will hopefully be expanded in the future for further studies on the topic.

COVID-19 caused or exacerbated negative health outcomes for many people, especially for those with pre-existing comorbidities. Sickle cell disease (SCD) is a rare genetic condition that primarily occurs among African Americans in the United States. At the time the pandemic started, there were a lot of unknowns. One, there was limited knowledge regarding how COVID-19 impacted individuals with SCD compared to those who do not have SCD or sickle cell trait.

Also, prior studies show that individuals with SCD have a higher risk of thrombosis. Some observations indicated that COVID-19 increases the risk of clotting and thrombosis, but more research was necessary to specifically define the impact of the virus on the population of SCD.

"We didn't know how COVID-19 impacts individuals with SCD compared to those who do not have SCD or if COVID-19 further exacerbates the already high risk of thrombosis in the sickle cell disease population," said Dr. Ashima Singh, Assistant Professor in the Department of Pediatrics Hematology at the Medical College of Wisconsin's (MCW) Institute of Health and Equity.

To help conduct the research needed to develop conclusive answers, the Institute leveraged the TriNetX platform to win a grant from the Children's Research Institute at MCW.

Research With a Focus on Rare Disease, Diverse Patient Populations

Dr. Singh has a PhD in Epidemiology and an MS in Biomedical Informatics, and her broad research interest involves knowledge discovery through real-world data (RWD). Dr. Singh is associated with the Medical College of Wisconsin, Division of Hematology/Oncology/BMT, Department of Pediatrics.

"I'm interested in understanding healthcare service utilization and clinical and patient-reported outcomes with sickle cell disease, a rare condition that predominantly occurs among African Americans," said Dr. Singh.

> “ *That's why a* ***source of real-world data*** *like TriNetX is ideal because of its conglomeration of patient data from many institutions. It provides the big data necessary to really help understand this population."*

Dr. Singh decided to pursue a grant that would help launch what will hopefully be an extended research project on the subject.

"The specific aims of the grant include understanding COVID-19 outcomes and also the prevalence of frequency of disease-related complications in children with Sickle Cell," said Dr. Singh. "The success measures for the grant would be publications of results and preparation for further study since this is a pilot grant with the understanding that we can expand to a larger grant down the road."

TriNetX Platform Key to Grant Award

"The TriNetX platform allowed us to get the numbers of patients we needed to show that it would be feasible to achieve the specific aims we were targeting," said Dr. Singh. "We were able to quickly assemble the demographics of the populations of interest. We didn't have much time to churn out the data. It would have been a great deal more difficult to come up with the data we needed or prospectively collect data to win the grant and do this study without TriNetX."

"The population of interest consisted of minorities and the strength of TriNetX is being able to access a large number of patients with sickle cell disease, much larger that we would have been able to get from just a single institution or an EHR review," she continued.

> “ *I have some experience with a few other platforms, but the TriNetX platform is very useful for researchers to look at preliminary patient data to determine the feasibility of the study," said Dr. Singh. "That type of data is not as readily available with some of the other networks I have worked with. And it's not just the availability of data, it's also* ***the ease of working with that data on the TriNetX platform****."*

Dr. Singh and her team have presented the study abstract and data at the American Society of Hematology and published the final manuscript in the August 2022 printing of Blood Advances: "**COVID-19 and venous thromboembolism risk in patients with sickle cell disease**."

"We are looking at the same data source to determine the risk of thromboembolisms among individuals with SCD who have COVID-19," said Dr. Singh. "In the current study we are comparing embolism rates among patients hospitalized for Sickle Cell disease and COVID-19 compared with those who are hospitalized for other causes and do not have COVID-19."

MCW excited by use of TriNetX platform

MCW's Biomedical Informatics team was an early adopter of the TriNetX platform and brought it to the organization through the Clinical & Translational Science Institute of Southeastern Wisconsin (CTSI) whose regional hub is at MCW. CTSI promotes TriNetX to its members as a valuable cohort discovery and analytics tool to facilitate research projects. The team at MCW believes other researchers can benefit from the use of the TriNetX platform.

> “ ***Using the TriNetX platform for feasibility*** *and then leveraging the data to* ***pursue grant funding*** *is something that we are really excited about," said Kristen Osinski, Business Analyst, Biomedical Informatics, CTSI at MCW.*

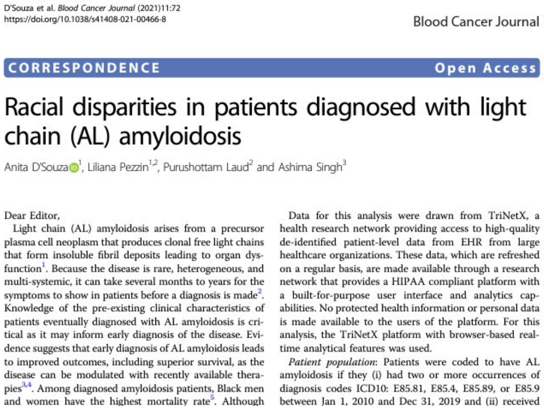
"We hope to expand the community of CTSI researchers interested in TriNetX as a data toolset because it can provide easy access to real-world data to facilitate and accelerate research across many healthcare, public health and basic science disciplines."

"The platform is particularly important when studying rare diseases like Sickle Cell," Dr. Singh summed up. "These diseases are typically difficult to understand based on the small numbers of patients involved...

> “ *...But* ***having a large data network like TriNetX*** *to study rare conditions is very much needed and should be leveraged so the individuals with those conditions don't go unrecognized or have a lack of understanding of what can be done to* ***improve their outcomes****."*

Other studies conducted using TriNetX platform

Dr. Singh and team are also collaborating with other investigators to leverage TriNetX data for other rare conditions. One of the studies, titled "**Racial disparities in patients diagnosed with light chain (AL) amyloidosis**" was published in the Blood Cancer Journal.



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Blood Cancer Journal

CORRESPONDENCE Open Access

Racial disparities in patients diagnosed with light chain (AL) amyloidosis

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Dear Editor,

Light chain (AL) amyloidosis arises from a precursor plasma cell neoplasm that produces clonal free light chains that form insoluble fibril deposits leading to organ dysfunction[1]. Because the disease is rare, heterogeneous, and multi-systemic, it can take several months to years for the symptoms to show in patients before a diagnosis is made[2]. Knowledge of the pre-existing clinical characteristics of patients eventually diagnosed with AL amyloidosis is critical as it may inform early diagnosis of the disease. Evidence suggests that early diagnosis of AL amyloidosis leads to improved outcomes, including superior survival, as the disease can be modulated with recently available therapies[3,4]. Among diagnosed amyloidosis patients, Black men and women have the highest mortality rate[5]. Although

Data for this analysis were drawn from TriNetX, a health research network providing access to high-quality de-identified patient-level data from EHR from large healthcare organizations. These data, which are refreshed on a regular basis, are made available through a research network that provides a HIPAA compliant platform with a built-for-purpose user interface and analytics capabilities. No protected health information or personal data is made available to the users of the platform. For this analysis, the TriNetX platform with browser-based real-time analytical features was used.

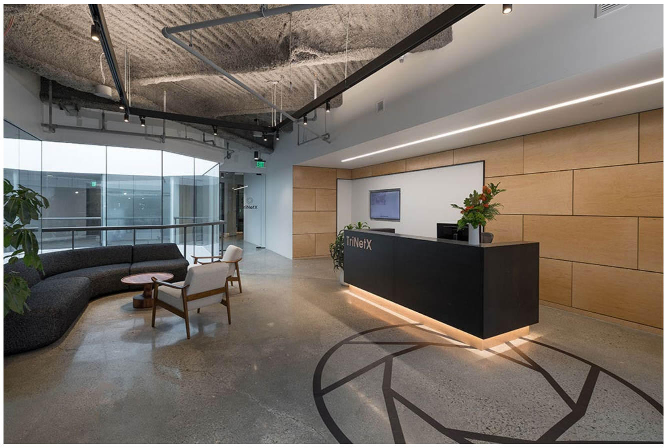
Patient population: Patients were coded to have AL amyloidosis if they (i) had two or more occurrences of diagnosis codes ICD10: E85.81, E85.4, E85.89, or E85.9 between Jan 1, 2010 and Dec 31, 2019 and (ii) received

About Medical College of Wisconsin

The Medical College of Wisconsin (MCW) is a privately run medical school whose headquarters are located just west of the city of Milwaukee, Wisconsin, in Wauwatosa. With a full-time enrollment of around 1,200 students, it is the largest research center in the Milwaukee metropolitan area. MCW offers graduate and postgraduate programs in Medicine, Pharmacy and other Health Related Sciences and is home to the Center for Infectious Disease Research. The medical school also doubles as a treatment facility for the surrounding population. For more information, visit **mcw.edu**.

About TriNetX, LLC

TriNetX is a global network of healthcare organizations and life sciences companies driving real-world research to accelerate the development of new therapies. Through its self-service, HIPAA, GDPR, and LGPD-compliant platform of federated EHR, datasets, and consulting partnerships, TriNetX puts the power of real-world data into the hands of its worldwide community to improve protocol design, streamline trial operations, refine safety signals, and enrich real-world evidence generation. For more information, visit TriNetX at **www.trinetx.com** or follow **@TriNetX** on Twitter.



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