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Assessing Patterns of Telehealth Use Among People with Sickle Cell Disease Enrolled in Medicaid During the Start of the COVID-19 Pandemic

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Author's Contributions
This study was conceptualized by S.L.R., S.T.P., A.B.S., M.P.S., and M.H. M.P., P.N.P., S.S.H., M.Z., A.P.P., and A.M. performed all state-specific data analyses. M.P. prepared all tables and figures. All authors reviewed and critically edited the manuscript.

Ethics Approval and Consent to Participate
Georgia: Use of these data was determined to be exempt from review as a public health surveillance activity by the Georgia State University Institutional Review Board (IRB). California: The CA SCDC Program and this study were reviewed and approved by the California Committee for the Protection of Human Subjects, the Public Health Institute IRB, and the IRBs at clinical sites reporting case data. CA SCDC received a waiver of consent. Michigan: Use of these data was determined to be exempt from review as a public health surveillance activity by the University of Michigan and Michigan Department of Health and Human Services IRBs. Tennessee: The SCDC-TN cohort is compiled, maintained, and analyzed with approval of the IRB of the Tennessee Department of Health and the Division of TennCare.
Informed consent was waived by the Georgia State University IRB, Public Health Institute IRB, California Committee for the Protection of Human Subjects, IRBs at clinical sites, the University of Michigan IRB, the Michigan Department of Health and Human Services IRB, the Tennessee Department of Health IRB, and the Division of TennCare IRB.
All methods were carried out in accordance with relevant guidelines and regulations.

Disclaimer
The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of the CDC.

Disclosure Statement
No competing financial interests exist.

Supplementary Material
Supplementary Figure S1
Supplementary Figure S2
Supplementary Table S1
Supplementary Table S2
Supplementary Table S3

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Abstract

Background: Telehealth can be defined as using remote technologies to provide health care. It may increase access to care among people with sickle cell disease (SCD). This study examined (1) telehealth use, (2) characteristics of telehealth use, and (3) differences between telehealth users and nonusers among people with SCD during the COVID-19 pandemic.

Methods: This was a retrospective analysis of Medicaid claims among four states [California (CA), Georgia (GA), Michigan (MI), Tennessee (TN)] participating in the Sickle Cell Data Collection program. Study participants were individuals ≥1 year old with SCD enrolled in Medicaid September 2019–December 2020. Telehealth encounters during the pandemic were characterized by provider specialty. Health care utilization was compared between those who did (users) and did not (nonusers) use telehealth, stratified by before and during the pandemic.

Results: A total of 8,681 individuals with SCD (1,638 CA; 3,612 GA; 1,880 MI; and 1,551 TN) were included. The proportion of individuals with SCD that accessed telehealth during the pandemic varied across states from 29% in TN to 80% in CA. During the pandemic, there was a total of 21,632 telehealth encounters across 3,647 users. In two states (MI and GA), over a third of telehealth encounters were with behavioral health providers. Telehealth users had a higher average number of health care encounters during the pandemic: emergency department (pooled mean = 2.6 for users vs. 1.5 for nonusers), inpatient (1.2 for users vs. 0.6 for nonusers), and outpatient encounters (6.0 for users vs. 3.3 for nonusers).

Conclusions: Telehealth was frequently used at the beginning of the COVID-19 pandemic by people with SCD. Future research should focus on the context, facilitators, and barriers of its implementation in this population.

Keywords

sickle cell disease; telehealth; administrative claims; Medicaid; telemedicine

Introduction

Sickle cell disease (SCD) is a group of inherited conditions that affects 100,000 individuals in the United States.[1] A majority of people impacted are within systematically marginalized communities.[2,3] SCD causes life-long issues with pain, stroke, and infection.[4] Routine medical care can reduce the morbidity experienced by those living with SCD. For example, evidence-based guidelines from the National Heart, Lung, and Blood Institute recommend receipt of numerous life-saving preventive services, such as medications, immunizations, and screenings.[4] These treatments can mitigate exacerbations of pain, prevent other complications (e.g., infection, stroke), and lengthen the lives of those who live with this debilitating condition.

Racial inequity exacerbates the significant health burden of SCD, resulting in increased vulnerability to adverse social determinants of health, such as poor housing, lack of insurance and transportation, and discrimination.[2,5,6] These are barriers to having access to quality care defined as the extent to which health care is affordable, available, accessible, accommodating, and acceptable to the individual.[2,7–10] For example, the costs of transportation and time off work have been shown to be a barrier to adherence to routine medical care.[11,12] There is also a shortage of health care providers comfortable managing individuals living with SCD.[13] Increasing access to quality care among individuals with SCD is essential to improve health outcomes, life expectancy, and quality of life.

Telehealth is defined as using remote technologies to manage health.[14] It can be delivered through multiple modalities, such as live video, asynchronous video, remote patient monitoring, and mobile health (e.g., use of apps). Importantly, telehealth has been shown to improve access to quality care for chronic conditions by reducing distance, transportation, and cost barriers.[15–18] For example, neurologists have used telehealth to treat patients with neurological diseases hundreds of miles away, when no local providers had the expertise to manage the patients’ conditions.[16] Driven by policy and cultural changes during the COVID-19 pandemic, there has been a nearly 10-fold increase in telehealth use among Medicaid beneficiaries.[19]

Telehealth use among individuals with SCD has also been growing; however, studies have been limited to pediatric or clinic-specific populations, single-state analyses, or survey respondents.[20–23] Therefore, there are unanswered questions regarding the use of telehealth among a broader population of people with SCD, including the frequency of use as well as characteristics of the telehealth use and users. Our objective was to examine (1) telehealth use, (2) characteristics of telehealth use, such as provider specialty and associated diagnoses, and (3) differences between telehealth users and nonusers in respect to demographics, area-level characteristics, and health services utilization during the beginning months of the pandemic.

Methods

This cross-sectional study uses Medicaid administrative claims data from four states to identify individuals with SCD and their use of telehealth before and during the start of the COVID-19 pandemic.

DATA SOURCES AND STUDY POPULATION

All study data were obtained from the California (CA), Georgia (GA), Michigan (MI), and Tennessee (TN) Sickle Cell Data Collection (SCDC) programs.[11,24,25] Briefly, the SCDC programs draw on multiple data sources to identify and longitudinally assess health care among individuals with SCD in each state. These data sources include newborn screening; nonfederal hospital discharge, emergency department, and ambulatory surgery encounters; vital records death files; Medicaid claims and enrollment data; and clinical case reports from

SCD care centers in the state. Data are linked and de-duplicated across data sources and years of data.

Each SCDC program applies a validated case definition to identify people with SCD in their state. An individual is classified as having SCD if any of the following criteria are met: (1) laboratory-confirmed newborn screening result for SCD; (2) laboratory confirmation of SCD (e.g., hemoglobin electrophoresis); or (3) at least three SCD-related health care visit claims over a 5-year time period.[26–28] Among all individuals with SCD, the following inclusion criteria were applied: (1) continuously enrolled in Medicaid September 2019–December 2020 (1 month enrollment gap allowed); and (2) at least 1 year of age at the beginning of the study period. All individuals dually enrolled in Medicaid and Medicare were excluded to ensure completeness of claims. All Medicaid administrative claims were obtained from September 2019 to December 2020 for the study population. Time before the start of the pandemic was included to assess health care utilization patterns prepandemic. Prepandemic was defined as September 2019–February 2020; during pandemic was defined as March 2020–December 2020.

Telehealth use.—All telehealth encounters were included. Telehealth encounters were identified in Medicaid administrative claims based on each state's Medicaid telehealth billing requirements, which include procedure modifier codes "GT," "GQ" or "95," place of service code "02," and telehealth service Healthcare Common Procedure Coding System codes.[29–31] All modes of telehealth administration (e.g., telephone, video, asynchronous) were included.

Characteristics of telehealth use.—Characteristics of telehealth use included provider specialty, new patient status (yes/no), and whether the encounter included an SCD-related diagnosis code. Provider specialty was determined using the National Provider Identifier for the visit provider linked to the National Plan and Provider Enumeration System.[32] Specialties were predefined by the study team and assigned following the hierarchy of hematologist, primary care (defined as pediatrics, family medicine, nurse practitioners, and physician assistants), behavioral health (defined as counselor, psychologist, social worker, or psychiatry or mental health), or other specialist (including any other provider not represented in the previously defined groups).[33] Provider specialty was unavailable for TN data.

New patient status of an encounter was determined using Common Procedural Terminology codes. Encounters were characterized as SCD-related if any International Classification of Diseases, Tenth Revision, Clinical Modification diagnosis code for SCD (D57) was associated with the encounter. We included this characterization, as we hypothesized that many telehealth visits, such as behavioral health, mental health, and therapies, may not include an SCD-related diagnosis.

Differences between telehealth users and nonusers.—Telehealth users were defined as having at least one telehealth encounter from March 2020 to December 2020. To assess differences among individuals who did (users) and did not (nonusers) use telehealth, the following categories of covariates were considered: demographics, area-level characteristics, and health services utilization. Age and sex were obtained from Medicaid enrollment files.

Area-level characteristics included rurality and an estimate of the level of broadband access. Estimate of the level of broadband access (i.e., enables ability to access Wi-Fi) was included as it may impact the ability to access telehealth.[34] Further, there are demonstrated disparities in broadband access.[35] These characteristics were assessed using the zip code of residence in Medicaid enrollment files in December 2020. Rurality was defined using the Rural-Urban Commuting Area Code with codes of 1–3 defined as urban (in a metropolitan area) and 4–10 as rural.[36] Level of broadband access, based on the percent of households with broadband, was obtained from 5-year estimates in the American Community Survey.[37] Individuals were defined as coming from a geographical region with high broadband access if the percent of households with access to broadband exceeded 80%. Health services utilization included the number of outpatient encounters, emergency department encounters, and acute inpatient admissions. Historical health services utilization was captured using claims data from the 6-month period before the pandemic (September 2019–February 2020).

STATISTICAL ANALYSIS

Demographics were assessed overall and by state. The percentage of individuals with at least one telehealth visit was calculated during the pandemic (March 2020–December 2020) and by month. Prepandemic telehealth use was calculated as the mean number of visits per person from September 2019 to February 2020. Characteristics of telehealth use included the mean, range, median, and interquartile range of the number of telehealth encounters among those that used telehealth. We calculated the proportion of visits occurring within each provider specialty, having an SCD-related diagnosis, and patient status (yes/no).

To assess differences among telehealth users and nonusers, we compared demographics, area-level characteristics, and health services utilization across both groups. Means and standard deviations or frequencies and percentages were calculated for demographics, area-level characteristics, and current and historic health services utilization by telehealth (yes/no). Independent sample *t*-tests compared the averages of utilization measures and patient age between individuals with at least one telehealth encounter during the pandemic and those without. Chi-square tests compared the distribution of sex, age group, and rurality between the two groups. Two sensitivity analyses were performed (1) expanding the comparison of demographic, area-level, and health services utilization by those with no, one, or two, or more telehealth encounters; and (2) examining the associations between health care utilization and telehealth use, stratified by pediatric (18 years and under) and adult (19+ years) populations.

Results

STUDY POPULATION AND TELEHEALTH USE

A total of 8,681 individuals (1,638 CA, 3,612 GA, 1,880 MI and 1,551 TN) with SCD met study inclusion criteria. Between 17.0% and 19.2% of individuals were previously excluded across states due to dual enrollment in Medicare and Medicaid. Compared to annual reports provided to the Centers for Disease Control and Prevention (CDC), the study population was inclusive of ~43% of the SCD population (5,891 in CA in 2018; 9,141 in GA in 2018; 3,505 in MI in 2018; 1,781 in TN in 2020).[38] Note the proportions vary across states given varying lengths of data collection efforts. Overall, 50.4% (n = 4,380) were pediatric (<18 years old) patients and 56.6% (n = 4,916) were female (Supplementary Table S1).

During the COVID-19 pandemic study period, 3,647 individuals (42%) accessed telehealth, which varied between states and months. All states saw an increase in telehealth use in March and April 2020; however, this declined thereafter (Fig. 1). This is in sharp contrast to prepandemic telehealth use, when the proportion of individuals with SCD who accessed telehealth services ranged from <5% in GA, MI, and TN to 59% in CA.

CHARACTERISTICS OF TELEHEALTH USE

Among telehealth users during the pandemic period, there were 21,632 telehealth encounters (Table 1). Consistent across states, new patient encounters made up only 2.2% of all telehealth encounters. In two states, GA and MI, around 70% of telehealth encounters had no SCD-related diagnosis, while in CA and TN, 72% and 45% of telehealth encounters had an SCD-related diagnosis listed, respectively. Specialty of the provider associated with the telehealth encounter was similar between GA and MI, in that behavioral health providers were among the most common and hematologists less common.

DIFFERENCES BETWEEN TELEHEALTH USERS AND NONUSERS

Except for CA, telehealth users had a significantly higher proportion of adult patients than pediatric patients compared with nonusers. Differences in sex were not observed between telehealth users and nonusers (Supplementary Table S1). Michigan and Tennessee saw a higher proportion of telehealth users from zip codes with high access to broadband compared with nonusers. This was not the case in GA, where significantly more nonusers came from high broadband areas compared to users (51.3% vs. 43.6%) (Supplementary Fig. S1).

Individuals who accessed care through telehealth had significantly higher average numbers of encounters for all three types of health care utilization (outpatient, emergency department, and inpatient) across all states, except for emergency department utilization in CA (Fig. 2). The largest differences were in the number of outpatient encounters; telehealth users across states had an average number of outpatient encounters that was nearly double those of nonusers. Individuals who accessed telehealth during the pandemic also tended to have higher historical health care utilization, with patterns being similar for utilization in the 6 months before the pandemic (Supplementary Fig. S2).

Sensitivity analyses indicated that individuals with two or more telehealth encounters tended to be older across the states compared to those with zero or one encounters. Additionally, utilization patterns increased as telehealth use increased (Supplementary Table S2). Associations between health care utilization and telehealth use remained across both the pediatric and adult populations, suggesting that age is not a confounder in the observed associations (Supplementary Table S3).

Discussion

In this study, at least one-third of individuals with SCD used telehealth during the pandemic across four state Medicaid programs. In California, this proportion was substantially higher, with as many as four out of five individuals with SCD using telehealth. Importantly, mental and behavioral health services were commonly provided through telehealth in Michigan and Georgia. Telehealth users in this study had more acute care utilization compared to telehealth nonusers. Although we were unable to ascertain drivers of this potential association, it is possible that telehealth was used by individuals with SCD that were having significant complications, such as pain or infection, which could result in acute care utilization.

Similar to other studies assessing the utilization of telehealth by people with SCD or other chronic conditions, there was a substantial increase in telehealth use as compared to the prepandemic period in all four states.[14,20,39,40] Notably, California had more than double the proportion of users of telehealth as compared to the other states and remained at sustained high levels after the initial months of the pandemic. Even before the pandemic, California had comprehensive telehealth policies in MedCal that supported a stronger infrastructure for telehealth use. Of the states included in this study, only California and Georgia require payment parity in Medicaid with private insurers.[41,42] California’s telehealth reimbursement policy also requires reimbursement for numerous types of telehealth delivery, such as text-based, remote patient monitoring, store-and-forward, and most asynchronous services.[43]

Many other state Medicaid programs increased access to telehealth through flexibilities only allowable during the COVID-19 Public Health Emergency.[44] In Michigan and Georgia, over one-third of telehealth encounters during the study period were provided by mental and behavioral health providers. In contrast, a previous study that looked at 2005–2012 data indicated that less than 7% of children with sickle cell anemia received mental or behavioral health services within a year, regardless of mode of delivery.[45]

Although research is lacking, a systematic review published in 2016 found prevalence estimates for depression in adults and children with SCD ranged from 2% to 57%, prevalence of anxiety in adults with SCD was reported as 6.5% in 2008, and one study from 2011 found that 50% of their sample of adolescents with SCD had psychiatric disorders.[46–48] The results of this study suggest that use of telehealth may be a feasible strategy to provide mental and behavioral health needs to people with SCD. However, this may be limited by a lack of mental and behavioral health providers with availability for services within states, as well as the prevalence of undiagnosed mental health conditions among this population.

Use of a surveillance system, such as SCDC, that utilizes a variety of data sources to identify individuals living with SCD is an essential strength of this study. This is particularly true during the COVID-19 pandemic, as changes in health care utilization patterns may impact the accuracy of case ascertainment methods that rely on a single-source administrative database.[49] However, there are limitations to consider in the interpretation of this study.

First, our study population included individuals who were continuously and exclusively enrolled in a state Medicaid program. Therefore, individuals who were dual eligible for Medicaid and Medicare had private insurance or were not continuously covered in Medicaid were excluded. The patterns of telehealth use may be different for these populations than those included in our study. Second, billing practices for telehealth across states may differ. For example, it is possible that telehealth encounters related to behavioral health were bundled with other services in some states. Further, if telehealth visits are reimbursed similarly to in-person visits, modifiers on telehealth claims were not necessary. These factors may account for the underrepresentation of behavioral health encounters in telehealth data in California.[50]

Third, this study represents only 9 months of the pandemic; as such, these findings may not extend to the entirety of the pandemic, particularly as health systems and insurers adapted to telehealth in the beginning months. Fourth, we were unable to account for any telehealth provided through third-party services. Fifth, we were unable to meaningfully categorize approximately one-third of telehealth providers beyond hematology, primary care, or mental and behavioral health. In general, limitations to this study would result in an underestimate of the use of telehealth among individuals with SCD during the pandemic.

Access to quality care is defined as the extent to which health care is affordable, available, accessible, accommodating, and acceptable to the individual.[7] Telehealth has the potential to increase the accessibility to care portion of the definition for people with SCD, particularly in connecting them to the limited number of health care providers who have expertise in managing their condition.[51] Telehealth appears to have been feasible for individuals with SCD to access care during the COVID-19 pandemic, particularly related to behavioral health. However, there are significant gaps in understanding the drivers of telehealth use among this population. Prepandemic research indicated that patients, caregivers, and health care providers generally perceive telehealth as a satisfactory modality of care.

However, as telehealth has expanded since the beginning of the pandemic, it will be important to understand changes in barriers and facilitators among this population.[21–23] Further, additional research is warranted to understand the effect of policies which encourage broad reimbursement for telehealth and programs, such as the Affordable Connectivity Program, which helps ensure that households can afford broadband for daily use.[52] Research focused on patient and family preferences, impact of telehealth use on acute care utilization, and provider-perceived barriers and facilitators to telehealth use could help to optimize telehealth for people with SCD.[36,53,54] In addition, it will be important to collect information on the quality of care provided through telehealth.[19] Without this input from key stakeholders, strategies to leverage telehealth to improve access to care among people with SCD may fall short of their potential to improve access to care and improve outcomes among this historically and systematically underserved population and intended outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Availability of Data and Materials

The datasets generated and analyzed during the current study are not publicly available due to restrictions on the sharing of state-specific Medicaid data, but aggregate data are available from the corresponding author on reasonable request and approval by state Medicaid programs.

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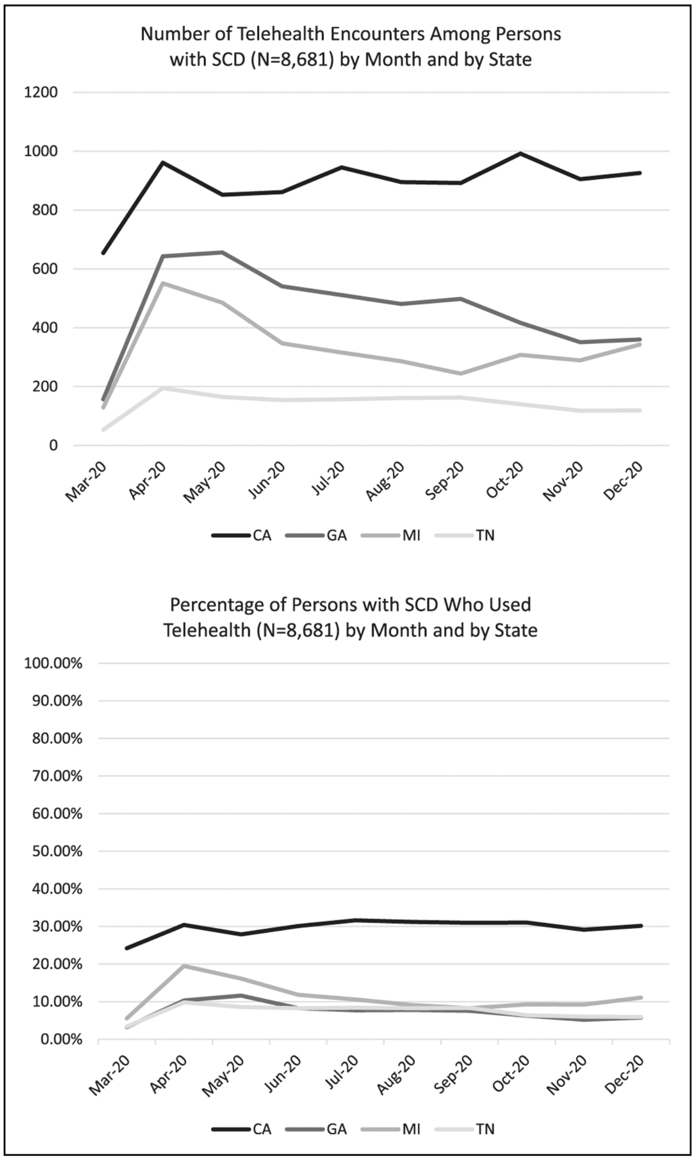

Fig. 1.

Telehealth use by state and month among individuals with SCD. CA, California; GA, Georgia; MI, Michigan; SCD, sickle cell disease; TN, Tennessee.

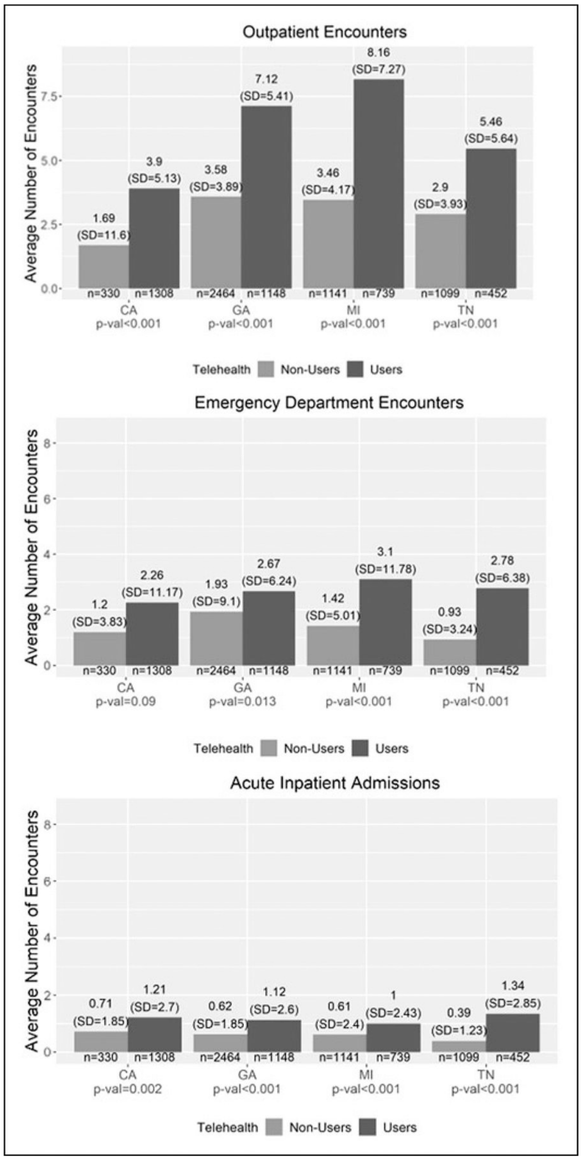

Fig. 2.

Health care utilization by telehealth use before and during the COVID-19 pandemic among individuals with SCD. SD, standard deviation.

Table 1.

Telehealth Use and Characteristics of Telehealth Encounters During the COVID-19 Pandemic Among Those Living With Sickle Cell Disease ($N = 8,681$)

	CALIFORNIA (*N* = 1,638)	**GEORGIA (*N* = 3,612)**	**MICHIGAN (*N* = 1,880)**	**TENNESSEE (*N* = 1,551)**
Telehealth users,[a] *n* (% of study population)	1,308 (79.9)	1,148 (31.8)	739 (39.3)	452 (29.1)
Telehealth encounters among users				
Mean [Min–Max]	6.79 [1–299]	4.02 [1–95]	4.47 [1–45]	3.15 [1–33]
Median (Q1, Q3)	4 (2, 8)	2 (1, 3)	2 (1, 5)	2 (1, 4)
Total telehealth encounters	12,294	4,615	3,298	1,425
SCD diagnosis, *n* (%)				
Yes	8,854 (72.0)	1,330 (28.8)	912 (27.7)	648 (45.5)
No	3,440 (28.0)	3,285 (71.2)	2,386 (72.3)	777 (54.5)
Provider specialty, *n* (%)				
Hematologist	4,223 (34.4)	688 (14.9)	418 (12.7)	NA[b]
Behavioral health	277 (2.3)	1,575 (34.1)	1,288 (39.1)	NA[b]
Primary care	3,316 (27.0)	767 (16.6)	1,260 (38.2)	NA[b]
Other	4,478 (34.4)	1,585 (34.3)	332 (10.1)	NA[b]

[a] Telehealth Users defined as individuals with at least one telehealth encounter during the pandemic period (March 2020–December 2020).

[b] Provider specialty data were not available for Tennessee.

Max, maximum; Min, minimum; SCD, sickle cell disease.