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# Letter to the Editor: Physicians' Opinions of COVID-19 Ambulatory Care Constraints

## A Survey of Sickle Cell Clinicians

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CORONAVIRUS DISEASE-2019 (COVID-19) has spread rapidly across the United States and has led to dramatic alterations to health care delivery within a short period (Cutler et al., 2020). Outpatient clinical volumes have declined as a consequence of changes in care delivery (Basu et al., 2020) and also in response to public health and government directives (Schweiberger et al., 2020). For many hospital systems and ambulatory centers, this has diminished revenue and caused some financial strain (Cutler et al., 2020; Khullar et al., 2020). Some ambulatory centers have had to restructure their daily operations while overcoming staffing and resource shortages (Kennedy et al., 2020) to minimize disruptions in access to outpatient services and continuity of care for individuals with chronic diseases.

There is fear that these alterations may have affected provision of care to especially vulnerable patients with sickle cell disease (SCD), an inherited hemoglobinopathy affecting approximately 100 000 individuals in the United States. The number of comprehensive SCD centers and sickle cell infusion centers (SCICs) in the United States is limited and far insufficient to meet the population need (Grosse et al., 2009; National Academies of Sciences Engineering et al., 2020). Poor disease outcomes appear to reflect the lack of

sickle cell providers (Lee et al., 2019). Outcomes have been shown to improve with comprehensive multidisciplinary outpatient SCD care (Kanter et al., 2020). Poor SCD outcomes stand in contrast to those of other inherited genetic disorders, such as cystic fibrosis and hemophilia, which have greater access to specialty care (Grosse et al., 2009; Lee et al., 2019).

However, the economic consequences of COVID-19 on outpatient centers (Basu et al., 2020; Provenzano et al., 2020) could potentially widen existing disparities in access to sickle cell care, by imposing increased strain on the financial and staffing resources of SCD centers. Adherence to recently published guidelines defining the key elements of adult comprehensive SCD care (Kanter et al., 2020) may have been stymied by the pandemic. Moreover, the called-for expansion of SCD centers by government entities (National Academies of Sciences Engineering et al., 2020) may have been delayed.

Therefore, to investigate the effect of pandemic-associated factors on SCD center ambulatory equipment, operations, personnel, and finances, we conducted an SCD center provider survey.

## METHODS

We utilized a cross-sectional study design to survey sickle cell physicians across the United States to assess the state of SCD clinics and centers during the COVID-19 pandemic. A purposive sampling approach was used to generate a list of eligible participants from the Sickle Cell Adult Provider Network (SCAPN) database [Po Box 4029, Evergreen, Colorado] and a complementary Internet search of SCD physicians. Respondents of another survey by the same project team were invited to participate if they were a physician who worked in a sickle cell clinic. Physician trainees, such as residents and fellows, and advanced providers were excluded. A sample of 100 individuals was considered eligible to participate in the study. Three external sickle cell experts assessed the survey for face validity and the SCAPN executive board reviewed the content. The Institutional Review Board (IRB) of UNC-Chapel Hill deemed the survey appropriate for an exemption.

The final survey was hosted on UNC-Chapel Hill's REDCap platform. Participants received 4 automated electronic invitations from December 14 to January 19, 2021, and the survey was closed to participation on January 26, 2021. Participants were asked to read a description of the study, funding disclosure, and provide consent prior to completing the survey questions. Participants answered questions regarding the baseline characteristics of their SCD clinic, impact of COVID-19 on "in-person" patient attendance, and operational changes made to their clinics and SCICs/day hospital in response to the pandemic.

REDCap was used to obtain descriptive statistics (means, standard deviations, percentages, and frequencies).

## RESULTS

Thirty-seven physicians from 27 unique SCD centers responded to the survey (37% response rate), and 32 physicians completed at least 90% of the survey. The demographics of the respondents and the sickle cell clinics are outlined in the Table. The overwhelming majority of the respondents practiced in teaching/academic hospitals in the Northeast or Southeast regions of the United States.

Most respondents reported that clinic-related factors, such as shortage of personal protective equipment, had little (31% of respondents) or no impact (44% of respondents) on patient clinic volume. Only 22% and 16% reported that a clinic administration-initiated decrease in scheduled appointments had a strong impact on clinic attendance. However, 68% of respondents agreed or strongly agreed with the statement "Covid-19-induced stress and anxiety has contributed to an increase in patient 'no show' rates or requests for rescheduling." To address these challenges with patients' clinic attendance, respondents reported using telemedicine often (64%) or always (21%).

The large majority (78%) reported that the deployment of clinic staff to assist with

**Table.** Characteristics of Survey Participants and Clinics

| Characteristics | n (%) |
|---|---|
| Age, y | |
| 30-39 | 7 (20) |
| 40-49 | 13 (37) |
| 50-59 y | 9 (26) |
| ≥60 y | 5 (14) |
| Gender | |
| Male | 18 (51) |
| Female | 17 (49) |
| Region of the United States | |
| Northeast | 10 (29) |
| Southwest | 1 (3) |
| West | 2 (6) |
| Southeast | 15 (43) |
| Midwest | 7 (20) |
| Practice type | |
| Teaching/academic hospital | 35 (100) |
| Age group | |
| Pediatric | 16 (46) |
| Adult | 17 (49) |
| Both | 2 (6) |
| Years in practice as a sickle cell physician | |
| <5 y | 7 (20) |
| 6-10 y | 7 (20) |
| 11-15 y | 8 (23) |
| 16-20 y | 5 (14) |
| >20 y | 8 (23) |
| Clinic patients/wk | |
| 5-10 | 2 (6) |
| 11-15 | 5 (15) |
| >15 | 27 (79) |
| Presence of day hospital/infusion center | |
| Yes | 26 (77) |
| No | 8 (24) |
| Average number of patients/d at SCIC[a,b] | |
| <5 | 17 (65) |
| 5-10 | 7 (27) |
| 11-15 | 2 (8) |
| Types of services at infusion center[b] | |
| Treatment for VOC | 21 (91) |
| Acute/sickle visits | 21 (91) |
| Blood transfusions | 22 (96) |
| Clinical trials | 11 (48) |
| Other | 2 (9) |

Abbreviations: SCIC, sickle cell infusion center; VOC, vaso-occlusive crisis.
[a]Sickle cell infusion clinic or day hospital.
[b]During the COVID-19 pandemic.

COVID-19 patients did not result in any staffing changes. Respondents also reported minimal percentages (mean 3.32%, range 0%-25%, and standard deviation 6.99) of clinical staff that were laid off or furloughed during the early months of the pandemic.

Of our respondents, 26 (77%) had an SCIC/day hospital. Infusion clinic's hours of operation remained largely the same compared with prepandemic hours, with 78% of respondents reporting no change in hours. The overwhelming majority (96%) made no modifications to the age range of the patients seen at their centers. Centers have implemented various procedural changes to varying degrees during the pandemic (Figure). Decrease in capacity/occupancy was the most common reported measure.

Fully 56% of respondents agreed or strongly agreed with the statement "prior to COVID, there was financial strain on my SCD center," while only 16% disagreed or strongly disagreed. In addition, 34% reported that their center/clinic had incurred additional operational costs due to COVID, and only 19% reported applying and/or receiving additional financial support while 25% were unsure whether their clinics had received additional funds.

## DISCUSSION

COVID-19 has led to significant changes in ambulatory care delivery. Significant reductions in staffing, procedural/operational changes, and decreased outpatient volume (Alexander et al., 2020; Basu et al., 2020) have affected routine care and treatment for diseases that are dependent on adequate access to outpatient subspecialty care (Kennedy et al., 2020). Moreover, as the short- and long-term clinical and economic consequences of the pandemic on health care systems—and on particularly ambulatory centers—become more apparent, it will be important to fully understand the impact on patient populations, such as patients with SCD, who have limited access to subspecialty care and poor disease outcomes.

It is now documented that structural racism has undeniably played a role in the disparities

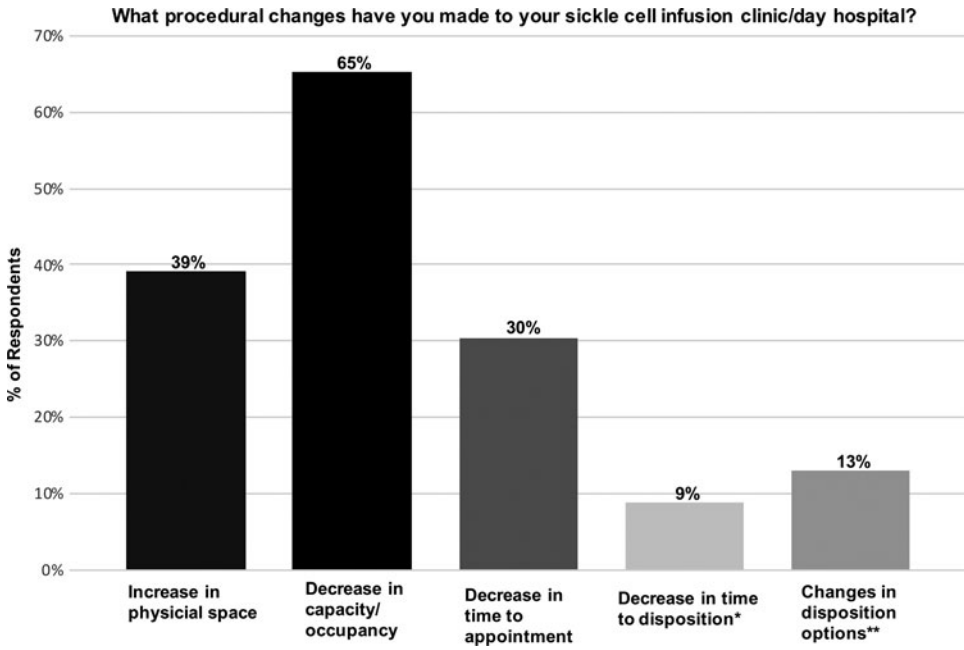


**Figure.** Procedural changes implemented at sickle cell infusion clinics (SCIC)/day hospitals during the COVID-19 pandemic. Participants were asked to check all that applied. *Interval from the initiation of treatment to discharge. **For example, direct admission to inpatient ward, bypassing emergency waiting room to emergency department bed.

in SCD care and outcomes (Power-Hays & McGann, 2020). However, our survey results imply that these existing disparities have not been drastically exacerbated as feared by the COVID-19 pandemic. We found that staffing reductions and operational changes have minimally affected the routine care provided by SCD clinics.

With respect to SCICs, most respondents reported decreased occupancy/capacity of their SCIC as a pandemic-induced procedural adaptation. In addition, 65% of respondents reported that fewer than 5 patients were seen on an average day at their SCIC during the pandemic. It is unclear how this volume compares to a prepandemic volume; however, the reduction in occupancy implies that overall patient volumes may have decreased during the pandemic. SCICs play a critical cost-efficient role in providing acute care services to patients with SCD by reducing inpatient admissions (Lanzkron et al., 2015). This is important because health care utilization costs of SCD are disproportionate to the prevalence of the disease within the United States (Lanzkron et al., 2010). The number of SCICs is inadequate for the current SCD population, and diminished capacity of the existing SCICs could drive up health care utilization among individuals with SCD. Future studies are needed to specifically examine patient access and volume at SCICs and corresponding trends in the utilization of their corresponding emergency departments and inpatient wards during the COVID-19 pandemic.

Experts believe that COVID-19 will likely become endemic in many areas (Aschwanden, 2021), suggesting that health care delivery will have to continue in the midst of ongoing COVID-19 infections. In addition, as outpatient clinical volumes resume to prepandemic levels, it will be critical to ensure that existing SCD centers and SCICs are maintained. Furthermore, to ensure that existing disparities in SCD care are not widened, vigilance is needed to ensure that SCD centers are not adversely affected by COVID-19 pandemic-induced budget reductions and resource reallocation at health care systems (Basu et al., 2020; Cutler et al., 2020).

When health care resources are limited, it is important to prioritize equity by ensuring adequate access to care for vulnerable patient populations, such as those with SCD.

Limitations of our study potentially include recall bias due to the length of recall period in our survey. Moreover, survey participants were surveyed at a time when there was a rapid shift to telemedicine (Hollander & Carr, 2020) and an overall decline in outpatient clinical volumes (Alexander et al., 2020). Thus, survey respondents may not have reported resource limitations if the overall patient burden had decreased. In addition, the evolving nature of the COVID-19 pandemic and public health government directives may have changed the conditions reported by our respondents since this survey. Further, nonresponse bias should be considered in interpreting our results, particularly given the lack of representation of nonacademic SCD physicians among our respondents. However, our response rate of 37% is comparable to online surveys of physician specialists (Cunningham et al., 2015). In addition, the self-reports of our respondents may not have been reflective of the true experience of the SCD clinic/center, particularly if a respondent did not have an administrative role, which allowed him/her to be privy to the staffing and resource allocation challenges of a center. Lastly, with 37 respondents from 27 different SCD centers, the experiences of a few centers may be overrepresented in our findings.

Despite these limitations, our study has, to our knowledge, provided the first assessment of pandemic-associated factors on SCD center ambulatory equipment, operations, personnel, and finances. Moreover, our results highlight the need for an additional follow-up survey and analysis of administrative databases to further gauge changes in resources, as outpatient volumes shift over time. In addition, qualitative studies should be conducted to further explore in detail pandemic-associated factors that may affect SCD centers. Such studies can provide clarity on specific operational/procedural adaptations and COVID-related financial strain on centers as well as highlight adaptations that are expected to persist beyond the pandemic.

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