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# Impact of COVID-19 pandemic on access to online therapeutic education programs for children with sickle cell disease

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## ABSTRACT

**Background:** Sickle cell disease (SCD) is a lifelong disease for which outcomes may be influenced by patients' self-care knowledge. Therapeutic education (TPE) is a patient-centered teaching instrument based on patient's adaptive processes and needs. TPE was developed in the Paris area by a pediatric health network using interactive face-to-face meetings. The COVID-19 pandemic has impacted the TPE modalities by promoting online training. Our aims were to evaluate the accessibility of patients with SCD to online TPE.

**Methods:** We compared sessions of TPE before and after the onset of the pandemic: the number of sessions, performed face-to-face or online, individual or in a group. We also recorded the number of participants in each session and their age, school level, and department in France.

**Findings:** We observed an increase in the total number of trained children, but participation varied greatly according to the geographical area of residence, with a decrease from 22.4% to 4.9% in the proportion of attendees living in the most socio-economically deprived French departments.

**Discussion:** Online TPE is feasible for patients with SCD but with unequal access according to socio-economic status.

**Application to practice:** Access to TPE needs to be improved for patients living in socially disadvantaged areas.

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## Background

Sickle cell disease (SCD) is one of the most common inherited blood disorders in the world. It is characterized by recurrent painful crises, chronic anemia with fatigue, severe infections, early onset of chronic organ damage, and premature death (Kanter et al., 2020; Osunkwo et al., 2021; Ware et al., 2017).

Pediatric mortality due to SCD has greatly decreased in recent years, related to neonatal screening and early implementation of prophylactic penicillin, prevention of stroke and hydroxyurea, along with parents' education to come to regular visits and go, when needed, to the

emergency department (De Montalembert et al., 2019; Desselas et al., 2020). Although information is most often provided by trained health-care professionals, a large proportion of parents of children with SCD do not follow recommendations such as regular visits or penicillin or hydroxyurea treatment (Hodges et al., 2020). Also, adherence to hydroxyurea is suboptimal in adolescents and young adults with SCD, which results in a significant decrease in health-related quality of life (Badawy et al., 2017). Patient education is important to improve disease management and well-being by increased self-care.

Several methods have been developed to enhance effective disease self-management in SCD: in-person or online education programs (Saulsberry et al., 2020; Shahine et al., 2015), apps (some using cognitive behavioral techniques) (Badawy et al., 2018; Crosby et al., 2017; Crosby et al., 2020; Hoods et al., 2021; Palermo et al., 2018; Schatz et al., 2015), and therapeutic education (TPE) (Fig. 1). TPE programs are individually tailored. They aim to help patients acquire and maintain self-care skills, with priorities defined by the patient, as well as "life" skills (self-confidence, control of stress, decision-making) using the

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**Fig. 1.** Available tools, possibly additive, for increasing self-care skills. SCD, sickle cell disease.

patient's previous experience. TPE is a four-step process: educational needs assessment, definition of the individual TPE program with learning priorities, TPE sessions, and assessment of the acquired skills (World Health Organization, 1998; [https://www.has-sante.fr/upload/docs/application/pdf/2008-12/therapeutic\\_patient\\_education\\_tpe\\_-\\_definition\\_goals\\_and\\_organisation\\_-\\_quick\\_reference\\_guide.pdf](https://www.has-sante.fr/upload/docs/application/pdf/2008-12/therapeutic_patient_education_tpe_-_definition_goals_and_organisation_-_quick_reference_guide.pdf)). So far, no report has described the use of TPE in patients with SCD, especially in children.

In our institution, we developed a unit for delivering TPE to parents and to children with SCD, called the Parisian Health Network *Réseau Francilien de Soins des Enfants Drépanocytaires* (RoFSED) and used it to provide face-to-face TPE sessions.

The COVID-19 pandemic has affected TPE strategies by stopping or greatly reducing direct contact and promoting online training. Several reports focusing on medical training for students have shown the benefits of innovative online teaching concepts (Badawy & Radovic, 2020; Gottschalk et al., 2021; Nourkami-Tutdibi et al., 2021). We were initially concerned because we had no experience with online training and feared poor Internet accessibility for some families. We developed strategies to continue offering TPE to children with SCD after the onset of the COVID-19 outbreak.

## Purpose

In this study, we report the strategies we developed in emergency to sustain delivering TPE to patients and families during the COVID-19 pandemic, compare the TPE procedures before and after the onset of the pandemic, and discuss the differences in participation in TPE sessions.

## Methods

### Setting of the study

TPE is usually delivered to children during face-to-face sessions, individually or in age-paired groups. The sessions are held in the RoFSED unit, located in the pediatric Necker-Enfants malades Hospital in Paris. The RoFSED network is funded by the Paris region Agency for Health (*Agence Régionale de Santé Ile de France*) and offers care to children

with SCD living in the Paris region. Children are referred by SCD expert centers, proximity healthcare centers, and more rarely by school professionals or families themselves. The main objectives are the coordination of care, scholar and psychological support, and TPE. Each year, approximately 250 children are followed up after parents have given their signed informed consent to be included in RoFSED programs.

### Organization of TPE in the pediatric Necker-Enfants malades Hospital

TPE is offered to all families with a child with SCD who is over 6 years old. About 50 families are asked to include their child in a TPE program each year, and approximately 30% of them accept. Until the COVID-19 pandemic, TPE sessions took place within RoFSED facilities in the Necker-Enfants malades Hospital.

TPE is delivered by healthcare professionals with specific training. Sessions are individual or in age-paired groups (4 to 8 children) and usually last 90 min. For children, TPE aims not only to improve treatment adherence but also to help them learn about their body, their needs, how to cope with the disease, and the role of preventive measures such as increasing hydration, avoiding getting cold, or warning their parents early when a new symptom occurs. Besides global information on their body, red blood cells, and SCD, children's representations of the disease are also discussed. Specific tools dedicated to SCD (available at [www.rofsed.fr](http://www.rofsed.fr)) and training sessions focused on hydration, pain, sport, and transition to adult care have been developed. Information and advice on COVID-19 and prevention have been added since the onset of the pandemic. Conferences and sessions are organized by the RoFSED, and access is free for all participants.

Before the pandemic, sessions were all face-to-face, either with individuals or groups. Parents were informed by mail or text messages of the occurrence of a session, according to the way the parents chose.

During the lockdown in France, no TPE was proposed. Since the end of the lockdown, group sessions have all been offered via a videoconferencing software, and individual sessions have been either face-to-face or online, using the same tool and according to the parents' will. A tutorial has been created to explain to parents and patients how to use the application, with the possibility of getting advice by phone when needed.

### Design of the study

#### Variables

In this study, we recorded the number of sessions, noting whether they were face-to-face or online and individual or group, the number of participants in each session, and the age, school level, and department of residence. A session was defined as a training organized for one or a group of patients. A teaching was defined as a lesson received by one patient. Age-paired groups of children were formed by grouping children according to their level of education (with groups for ages 6–10, 11–14, and 15–20 years). The departments where the families lived were recorded, all in the Paris region, including Paris and 7 neighboring departments, in alphabetical order: Essonne, Hauts de Seine, Seine et Marne, Seine Saint Denis, Val de Marne, Val d'Oise, and Yvelines. The annual income per household varies greatly between Paris and other departments, ranging from 21,768 Euros for Seine St Denis, one of the poorest departments in France, to 48,301, 45,966 and 40,281 Euros for Paris, Hauts de Seine and Yvelines, respectively, the 3 wealthiest departments of France (data from the French Minister of Economy, 2019) (<https://www.journaldunet.com>).

We compared TPE activity between 2018 and 2020, given that in France the first lockdown took place from March 16 to May 11, 2020 and social distancing was still highly recommended after May 2020. We chose the year 2018 for the pre-outbreak period, because the year 2019 was marked by major transportation strikes in the Paris area, which could have affected the ability of parents to come to Necker

**Table 1**  
Description of the therapeutic education (TPE) activities.

	2018	2020	P
Number of children who had at least 1 TPE session	49	41	
Number of sessions (individual/group)	18 (7/11)	35 (24/11)	
Number of teachings	61	71	
Number of sessions per child: mean (SD)	1.24 (0.52)	1.73 (1.60)	0.047*
range	1–3	1–9	

\* Comparison between 2018 and 2020, using a Student *t*-test.

Hospital, and, hence, TPE activity. The number of TPE sessions per child was compared by Student *t*-test.

*Ethical considerations*

The local ethics committee was consulted for this study and considered that the research did not require additional ethics approval after signed informed consent was obtained from parents for inclusion in the RoFSED.

**Findings**

The age distribution of participants did not change significantly between 2018 and 2020: 40% to 45% were 6–10 years old; one third 10–14 years old, and 20% to 26% ≥ 14 years old. Table 1 summarizes the number of children who had at least one TPE session in 2018 and 2020, the total number of sessions, total number of teachings, and mean number of sessions per child. The number of children who had at least one TPE session was stable over the period (about 45 per year). However, the number of sessions increased considerably in 2020, with a total of 35 sessions, including 24 online (as compared with 18 sessions in 2018, not online). The total number of teachings increased from 61 to 71 between 2018 and 2020. The mean number of sessions per child (individually or group) increased from 1.2 ± 0.5 (range 1–3) in 2018 to 1.7 ± 1.6 (range 1–9) in 2020, mainly because of a 3-fold increase in the number of individual sessions. Many children who received at least one individual session in 2020 asked to participate in group sessions afterwards, which was not the case when individual sessions were proposed only face-to-face.

Participation varied greatly according to the geographical area of residence, with a major decrease from 22.4% to 4.9% in attendees living in Seine saint Denis, one of the most socio-economically deprived French departments. This decrease contrasts with an increased proportion of patients living in Paris and Hauts de Seine, two of the most advantaged French departments (Fig. 2). The number of children from each department is given in Fig. 3.

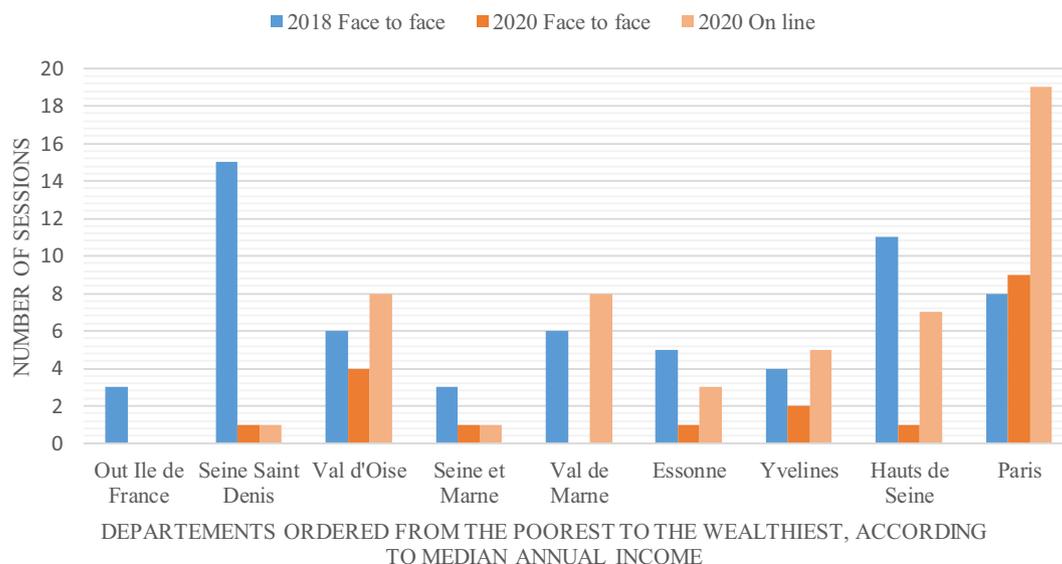
**Discussion**

*Retrospective analysis of implementation*

SCD is a chronic disease that predominantly affects people of Afro-Caribbean origin [Osunkwo et al., 2021; Hassell, 2010]. Quality of life, life expectancy, and lifetime income are lower in patients with SCD than matched individuals without SCD in the United States (Lubeck et al., 2019) and in France (unpublished data). Self-care interventions enhancing access to education and self-efficacy have been developed, mostly for adolescents and young adults. However, in clinics, education programs are poorly attended.

Cognitive behavioral techniques (CBTs), many of them accessed by mobile apps, have been used for SCD adolescents and young adults in different programs, with interesting results (Badawy et al., 2018; Crosby et al., 2020; Hoods et al., 2021; Palermo et al., 2018; Schatz et al., 2015). Young patients' motivation is increased when using mobile technologies, desktop/laptop computers or mobile phones, even more so if apps are patient-centered and with interactive/social features (Crosby et al., 2017). In the United States, the CaRISMA study is comparing the effectiveness of education delivered by mobile phones in adults, using CBT or pain and SCD education, with results expected in 2023 (ClinicalTrials.gov: NCT04419168) (Badawy et al., 2021). CBT is delivered by psychologists or behavioral pain specialists.

TPE is a different tool, delivered by a stakeholder after at least 40 h of training, which allows for non-SCD-specialized physicians and nurses as well as patients to receive the training. According to the World Health Organization definition, TPE helps patients acquire or maintain the skills they need to manage their life in the best possible way (World Health Organization, 1998; [https://www.has-sante.fr/upload/docs/application/pdf/2008-12/therapeutic\\_patient\\_education\\_tpe\\_-\\_definition\\_goals\\_and\\_organisation\\_-\\_quick\\_reference\\_guide.pdf](https://www.has-sante.fr/upload/docs/application/pdf/2008-12/therapeutic_patient_education_tpe_-_definition_goals_and_organisation_-_quick_reference_guide.pdf)). It is a 4-step procedure, involving an educational diagnosis; defining an individually tailored TPE



**Fig. 2.** Number of therapeutic education sessions in 2018 and 2020 according to departments in France.

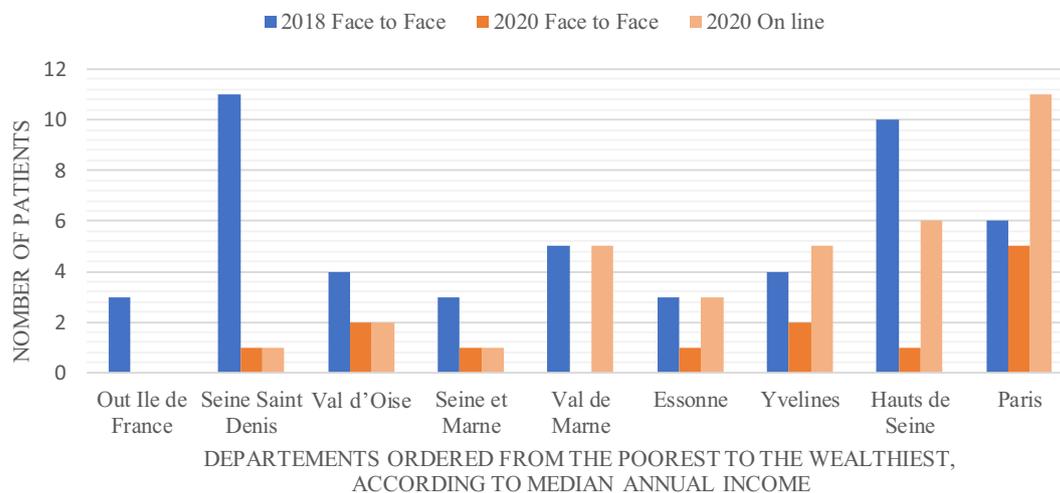


Fig. 3. Number of children attending therapeutic education sessions in 2018 and 2020 according to departments in France.

program with learning priorities; planning and providing individual or group sessions, or both, in alternation; assessing the skills acquired; and program implementation. A key feature is to take into account the patient's experience of the disease in the TPE program. Regular follow-ups consider when the patient needs to revise their goals and educational procedure and update the educational diagnosis. TPE has been mostly used in patients with diabetes and hemophilia (Baudrant et al., 2007; Wintz et al., 2010). SCD was not mentioned by the World Health Organization report in 1998, which listed only hemophilia and thalassemia in the group of blood disorders that could benefit from TPE (World Health Organization, 1998). Children with SCD are now recognized as good candidates for TPE, although we were not able to find any published tool for TPE for SCD patients in the literature. We have now 10 years of experience with TPE in children with SCD, beginning after age 6 years, and have developed educational tools adapted for children (available at [www.rofsed.fr](http://www.rofsed.fr)).

Our study did not aim to evaluate the effectiveness of TPE in children with SCD because it is currently being evaluated in an ongoing randomized study (ClinicalTrials.gov: NCT03786549) (Hoegy et al., 2020). Rather, it aimed to assess the feasibility of continuing TPE during the COVID-19 pandemic. We found that providing sessions online was associated with an increase in the total number of sessions per child. However, the participation in online sessions seemed easier for children and families living in departments with higher family incomes. In these departments, TPE was attractive enough to encourage children to attend more sessions. The increased participation in TPE may have been associated with the families being confined to home and therefore able to participate without the burden of transportation and with the ability to sign out at any time, which constitutes significant advantages for patients. In some cases and upon the parents' request, sessions were performed later in the evening to allow parents and children to attend more easily. In the youngest age groups (6–10 years for sure and probably also 11–14 years), the app was initially driven by the parents, but it soon seemed that children were at least as confident as their parents in using the app. The high level of stress related to the COVID-19 pandemic likely contributed to the interest in online discussions, and over the same period, the RoFSED developed psychological support, which helped children and families communicate their fears and questions. Of note, the increase in number of sessions resulted from an increase in the number of individual trainings, but the number of group sessions did not change, which may be related to worrying about being in group after the pandemic onset.

That families living in the most socio-economically deprived French department had less use of TPE may have several explanations. For online sessions, we speculate that reduced access to the Internet and more

difficulty using the app are possible causes. For face-to-face sessions, families living in more crowded conditions may have had fears related to COVID-19 and hesitated to use public transportation. Furthermore, in the more affluent areas, parents may have had jobs from which they were able to work from home and provide supervision for online sessions and app usage, while those in the less affluent areas may have needed to be outside the home to work and were less available to schedule or participate in sessions.

#### Evidence application to Practice and Research implication

This work has been led in France, where TPE is more developed than CBT techniques, one possible reason being that it can be used by a large panel of stakeholders after a training of 40 h. As TPE combines largely otherwise used psychological, social, and medical approaches, we assume our observations using this technique can be transposable to other self-care techniques in different other countries.

Whatever the causes, socioeconomic deprivation seems a risk factor for less access to information and self-care knowledge. Poverty in children with SCD was previously found associated with not only reduced quality of life but also increased pain burden and healthcare utilization (Lee et al., 2019; Panepinto et al., 2009; Raphael et al., 2009). COVID-19 appears to amplify the disparities in healthcare provision for socio-economically deprived children with SCD.

#### Limitation

Our study has several limitations, such as a single-center recruitment and small simple size. We did not assess individual socio-economic characteristics or parental education levels. Also, we did not evaluate the efficacy of our TPE program. Finally, we did not control for parent and child satisfaction with the sessions and would like to implement a questionnaire comparing the clarity and comprehensibility of online and face-to-face sessions.

#### Conclusions

The COVID-19 pandemic has brought an urgent need to enhance digital approaches to healthcare (Badawy & Radovic, 2020). Our findings show that patients and families may find interest in these tools, which could help in patients' daily lives. However, access to these interventions is likely unequal, with the risk of enhancing pre-existing social disparities [Abman et al., 2020]. Increasing access to online training can help optimize healthcare equity and address disparities in access to care

related to race and ethnicity and socioeconomic status. There is need for future research, in particular an assessment of the safety and efficacy of digital tools in SCD and the possibility to offer such tools equally to all patients and families.

### Conflicts of interest

The authors have no financial relationship relevant to this article to disclose.

### Credit authorship contribution statement

**Alizee Sterlin:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Validation, Writing – original draft, Writing – review & editing. **Mariane de Montalembert:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Validation, Writing – original draft, Writing – review & editing. **Melissa Taylor:** Investigation, Writing – review & editing. **Sandrine Mensah:** Investigation, Writing – review & editing. **Marie Vandaele:** Investigation, Writing – review & editing. **Agathe Lanzeray:** Investigation, Writing – review & editing. **Louise Poiraud:** Investigation, Writing – review & editing. **Slimane Allali:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Validation, Writing – original draft, Writing – review & editing.

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### References

- Abman, S. H., Bogue, C. W., Baker, S., Carlo, W., Daniels, S. R., De Baun, M. R., ... American Pediatric Society (2020). Racism and social injustice as determinants of child health: The American pediatric society issue of the year. *Pediatric Research*, 88(5), 691–693. <https://doi.org/10.1038/s41390-020-01126-6>.
- Badawy, S. M., Abebe, K. Z., Reichman, C. A., Checo, G., Hamm, M. E., Stinson, J., Lalloo, C., Carroll, P., Saraf, S. L., Gordeuk, V. R., Desai, P., Shah, N., Liles, D., Trimmell, C., & Jonassaint, C. R. (2021). Comparing the effectiveness of education versus digital cognitive behavioral therapy for adults with sickle cell disease: protocol for the cognitive behavioral therapy and real-time pain management intervention for sickle cell disease via mobile applications (CaRISMA) study. *JMIR Research Protocols*, 10(5) Article e29014. <https://doi.org/10.2196/29014>.
- Badawy, S. M., Cronin, R. M., Hankins, J., Crosby, L. E., DeBaun, M., Thompson, A. A., & Shah, N. (2018). Patient-centered eHealth interventions for children, adolescents, and adults with sickle cell disease: Systematic review. *Journal of Medical Internet Research*, 20(7) Article e10940. <https://doi.org/10.2196/10940>.
- Badawy, S. M., & Radovic (2020). A. Digital approaches to remote pediatric health care delivery during the COVID-19 pandemic: existing evidence and a call for further research. *JMIR Pediatr Parent*, 3(1), Article e20049. <https://pediatrics.jmir.org/2020/1/e20049>.
- Badawy, S. M., Thompson, A. A., Lai, J. S., Penedo, F. J., Rychlik, K., & Liem, R. I. (2017). Health-related quality of life and adherence to hydroxyurea in adolescents and young adults with sickle cell disease. *Pediatric Blood & Cancer*, 64(6). <https://doi.org/10.1002/pbc.26369>.
- Baudrant, M., Allenet, B., Le Tallec, C., Grangeat, M., & Calop, J. (2007). Educating diabetic children: Integrating representations by children aged 7 to 11 and their parents. *Pharmacy World & Science*, 29(6), 699–703. <https://doi.org/10.1007/s11096-007-9117>.
- Crosby, L. E., Hood, A., Kidwell, K., Nwankwo, C., Peugh, J., Strong, H., ... Britto, M. T. (2020). Improving self-management in adolescents with sickle cell disease. *Pediatric Blood & Cancer*, 67(10), Article e28492. <https://doi.org/10.1002/pbc.28492>.
- Crosby, L. E., Ware, R. E., Goldstein, A., Walton, A., Joffe, N. E., Vogel, C., & Britto, M. T. (2017). Development and evaluation of iManage: A self-management app co-designed by adolescents with sickle cell disease. *Pediatric Blood & Cancer*, 64(1), 139–145. <https://doi.org/10.1002/pbc.26177>.
- De Montalembert, M., Tshilolo, L., & Allali, S. (2019). Sickle cell disease: a comprehensive program of care from birth. *Hematology. American Society of Hematology. Education Program*, 1, 490–495. <https://doi.org/10.1182/hematology.2019000053>.
- Desselas, E., Thuret, I., Kaguelidou, F., Benkerrou, M., de Montalembert, M., Odievre, M. H., ... Brousse, V. (2020). Mortality in children with sickle cell disease in mainland France from 2000 to 2015. *Haematologica*, 105(9), e440–e443. <https://doi.org/10.3324/haematol.2019.237602>.
- Gottschalk, M., Werwick, K., Albert, C., Weinert, S., Schmeisser, A., Stieger, P., & Braun-Dullaeus, R. C. (2021). Digitalization of presence events in the COVID-19 pandemic—the lecturers' perspective. *GMS Journal of Medical Education*, 38(1) Doc30 <https://doi.org/10.3205/zma001426>.
- Hassell, K. L. (2010). Population estimates of sickle cell disease in the US. *American Journal of Preventive Medicine*, 38(4 Suppl), S512–S521. <https://doi.org/10.1016/j.amepre.2009.12.022>.
- Hodges, J. R., Phillips, S. M., Norell, S., Nwosu, C., Khan, H., Luo, L., ... Porter, J. (2020). Intentional and unintentional nonadherence to hydroxyurea among people with sickle cell disease: A qualitative study. *Blood Advances*, 4(18), 4463–4473. <https://doi.org/10.1182/bloodadvances.202001701>.
- Hoegy, D., Bleyzac, N., Gauthier-Vasserot, A., Cannas, G., Denis, A., Hot, A., ... DREPADO study group (2020). Impact of a paediatric-adult care transition programme on the health status of patients with sickle cell disease: Study protocol for a randomized controlled trial (the DREPADO trial). *Trials*, 21(1), 152. <https://doi.org/10.1186/s13063-019-4009-9>.
- Hoods, A., Nwankwo, C., Walton, A., McTate, E., Joffe, N., Quinn, C. T., ... Crosby, L. E. (2021). Mobile health use predicts self-efficacy and self-management in adolescents with sickle cell disease. *Translational Behavioral Medicine*, 11(10), 1823–1831 <https://doi.org/10.1093/tbm/ibab041>.
- Kanter, J., Smith, W. R., Desai, P. C., Treadwell, P. C., Andemariam, B., Little, J., ... Lanzkron, S. (2020). Building access to care in adult sickle cell disease: Defining models of care, essential components, and economic aspects. *Blood Advances*, 4(16), 3804–3813 <https://doi.org/10.1182/bloodadvances.202001743>.
- Lee, L., Smith-Whitley, K., Banks, S., & Puckrein, G. (2019). Reducing health care disparities in sickle cell disease: A review. *Public Health Reports*, 134(6), 599–607. <https://doi.org/10.1177/003335491881438>.
- Lubeck, D., Agodoa, I., Bhakta, N., Danese, M., Pappu, K., Howard, R., Gleeson, M., Halperin, L., & Lanzkron, S. (2019). Estimated life expectancy and income of patients with sickle cell disease compared with those without sickle cell disease. *JAMA Network Open*, 2(11) Article e19153774. <https://doi.org/10.1001/jamanetworkopen.2019.15374>.
- Nourkami-Tutdibi, N., Hofer, M., Zemlin, M., Abdul-Haliq, H., & Tutdibi, E. (2021). Teaching must go on: Flexibility and advantages of peer assisted learning during the COVID-19 pandemic for undergraduate medical ultrasound education- perspective from the “sonoBYstudent” ultrasound group. *GMS J Med Educ*, 38(1) Doc5 <https://doi.org/10.3205/zma001401>.
- Osunkwo, I., Andemariam, B., Minniti, C. P., Inusa, B., El Rassi, F., Francis-Gibson, B., ... James, J. (2021). Impact of sickle cell disease on patients' daily lives, symptoms reported, and disease management strategies: Results from the international sickle cell world assessment survey (SWAY). *American Journal of Hematology*, 96(4), 404–417 <https://doi.org/10.1002/ajh.26063>.
- Palermo, T. M., Zempsky, W. T., Dampier, C. D., Lalloo, C., Hundert, A. S., Murphy, L. K., ... Stinson, J. N. (2018). iCan cope with sickle cell pain: Design of a randomized controlled trial of a smartphone and a web-based pain self-management program for youth with sickle cell disease. *Contemporary Clinical Trials*, 74, 88–96. <https://doi.org/10.1016/j.cct.2018.10.006>.
- Panepinto, J., Foerster, L., Sabnis, S., Pajewski, N., & Hoffmann, R. (2009). Impact of poverty and sickle cell disease on the health-related quality of life of children. *Quality of Life Research*, 18(1), 5–13. <https://doi.org/10.1007/s11136-008-9412-8>.
- Raphael, J., Dietrich, C., Whitmire, D., Mahoney, D., Mueller, B. U., & Giardino, A. P. (2009). Healthcare utilization and expenditures for low-income children with sickle cell disease. *Pediatric Blood & Cancer*, 52(2), 263–267. <https://doi.org/10.1002/pbc.21781>.
- Saulsberry, A. C., Hodges, J. R., Cole, A., Porter, J. S., & Hankins, J. (2020). Web-based technology to improve disease knowledge among adolescents with sickle cell disease: Pilot study. *JMIR Pediatr Parent*, 3(1), Article e15093. <https://doi.org/10.2196/15093>.
- Schatz, J., Schlenz, A., McLellan, C. B., Puffer, E. S., Hardy, S., Pfeiffer, M., & Roberts, C. W. (2015). Changes in coping, pain and activity following cognitive-behavioral training: a randomized clinical trial for pediatric sickle cell disease using smartphones. *The Clinical Journal of Pain*, 31(6), 536–547. <https://doi.org/10.1097/AJP.0000000000000183>.
- Shahine, R., Kurdadi Badr, L., & Abboud, M. (2015). Educational intervention to improve the health outcomes of children with sickle cell disease. *Journal of Pediatric Health Care*, 29(1), 54–60. <https://doi.org/10.1016/j.pedhc.2014.06.007>.
- Ware, R. E., de Montalembert, M., Tshilolo, L., & Abboud, M. R. (2017). Sickle cell disease. *Lancet*, 390(10091), 311–323. [https://doi.org/10.1016/S0140-6736\(17\)30193-9](https://doi.org/10.1016/S0140-6736(17)30193-9).
- Wintz, L., Sannié, T., Ayçaguer, S., Guerois, C., Bernhard, J. P., Valluet, D., ... Gagnayre, R. (2010). Patient resources in the therapeutic education of haemophiliacs in France: Their skills and roles as defined by a consensus working group. *Haemophilia*, 16(3), 447–454. <https://doi.org/10.1111/j.1365-2516.2009.02163x>.
- World Health Organization (1998). *Therapeutic patient organization*.