Impact of COVID-19 pandemic on access to education programs for children with sickle cell disease and social deprivation: a qualitative study

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Abstract

Background: Sickle cell disease is a lifelong disease for which health outcomes may be greatly influenced by patient and parent self-care knowledge and skills. Therapeutic education (TPE) is a patient-centered teaching instrument, based on patient adaptative processes and their subjective and objective needs, whether expressed or not. TPE is delivered in individual or group sessions, usually during face-to-face meetings. The COVID-19 pandemic has impacted the modalities of TPE by promoting online training. The RoFSED health network, which operates in the Paris region and is focused on coordination of care and TPE for children with SCD, has implemented online TPE since May 2020.

Objective: To evaluate the accessibility of children with SCD to online TPE.

Methods: Characteristics of TPE before and after the onset of the pandemic were compared to evaluate the accessibility of children with SCD to online TPE.

Results: We observed an increase in the total number of trained children, mostly related to increased participation in individual sessions. The age distribution of participants did not vary. However, participation varied greatly according to the geographical area of residence, with a major drop from 22.4 to 4.9% of attendees living in Seine saint Denis, one of the most socio-economically deprived French departments, contrasting with an increased proportion of attendees living in Paris and Hauts-de-Seine, two of the most favoured French departments.

Conclusions: Our results highlight the potential of online TPE tools for patients and families with SCD but also reveal unequal access according to socio-economic status. Future research is needed, in particular on the safety and efficacy of these tools, as well as on improving access for the more vulnerable patients living in socially disadvantaged areas.

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ABSTRACT

Background: Sickle cell disease is a lifelong disease for which health outcomes may be greatly influenced by patient and parent self-care knowledge and skills. Therapeutic education (TPE) is a patient-centered teaching instrument, based on patient adaptative processes and their subjective and objective needs, whether expressed or not. TPE is delivered in individual or group sessions, usually during face-to-face meetings. The COVID-19 pandemic has impacted the modalities of TPE by promoting online training. The RoFSED health network, which operates in the Paris region and is focused on coordination of care and TPE for children with SCD, has implemented online TPE since May 2020.
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Conclusions: Our results highlight the potential of online TPE tools for patients and families with SCD but also reveal unequal access according to socio-economic status. Future research is needed, in particular on the safety and efficacy of these tools, as well as on improving access for the more vulnerable patients living in socially disadvantaged areas.

KEYWORDS
Therapeutic education; self-care; COVID-19; sickle cell disease; chronic disease; eHealth.

INTRODUCTION

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 [1-3]. A dramatic decrease in pediatric mortality has been observed in recent years, related to neonatal screening and early implementation of prophylactic penicillin, prevention of strokes and hydroxyurea, along with parent education to come to regular visits and go, when needed, to the emergency department [4,5]. Although education 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 taking penicillin or hydroxyurea [6]. Also, adherence to hydroxyurea is very suboptimal in adolescents and young adults with SCD, resulting in significant declines in health-related quality of life [7]. Patient education is important to improve disease management and well-being through increased self-care. Among the multiple tools available, therapeutic education (TPE) is a key instrument, based on patients' specific needs. It aims to help patients acquire the skills to self-manage or adapt treatment to their particular chronic disease, as well as learn coping processes and skills. TPE integrates the patient's adaptative processes, coping mechanisms with chronic disease, health beliefs, socio-cultural perceptions, as well as both subjective and objective needs of the patient, whether expressed or not [8]. In our institution, we developed a unit for delivering TPE to parents and children affected with SCD, called the Parisian Health Network RoFSED (for Réseau Francilien de Soins des Enfants Drépanocytaires). TPE in children not only aims 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. TPE is usually delivered to children during face-to-face sessions, individually or in age-paired groups.

COVID-19 pandemic has impacted TPE strategies by stopping or drastically reducing direct contact and promoting online training. Several reports focusing on medical training for students have shown the benefits of innovative online teaching concepts [9]. But there is, to date, no report on online TPE for children with SCD.

Objectives

Here we report the strategies we developed to continue offering TPE to children with SCD after the onset of COVID-19 outbreak. We were initially concerned as we had no experience with online training and feared poor internet accessibility for some families. In this study, we compare the TPE procedures before and after the onset of the pandemic, and discuss the differences observed in participation in TPE sessions.

METHODS

The RoFSED is located in the pediatric Necker-Enfants malades Hospital in Paris. It is granted by the Parisian 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 by families themselves. The main objectives are the coordination of care, scholar and psychological support, and TPE. Each year, approximately 200 children are followed-up after parents have given their signed informed consent to be included in RoFSED programs. TPE is offered to all families with an SCD child over 6 years old, and among them, around 50 families, approximately 30% of them, accept each year. Until COVID-19 pandemic, TPE sessions took place within RoFSED facilities in the Necker-Enfants malades Hospital in Paris.

TPE is delivered by health care professionals with specific training. Sessions are individual or in age-paired groups (gathering 4 to 8 children) and usually last 90 minutes. 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 and training sessions focused on hydration, pain, sport, and transition to adult care have been developed [10]. Information and prevention advice on COVID-19 and prevention has also been added after the onset of the pandemic. Conferences and sessions are organized by the RoFSED and access is free for all participants.

In this study, we recorded the number of sessions, noting whether they were face-to-face or online and individual or in group, the number of participants in each session, the age, school level, and department of the participants. 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 gathering children according to their level of education (with groups of children aged 6-10, 11-14, and 15-20 years old). 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 by fiscal household varies greatly between Paris and other departments, ranging from 21 768 Euros for Seine St Denis, which is one of the poorest departments in France, to 48 301, 45 966 and 40 281 Euros for Paris, Hauts de Seine and Yvelines, respectively, which are the 3 wealthiest departments of France (data from the French Minister of Economy, 2019) [11].

We compared the 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 transport strikes which could have had an impact on TPE activity.

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

RESULTS

Prior to the pandemic, sessions were all in face-to-face, either individual or in groups. During the lockdown, 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. Table 1 summarizes the number of children who had at least one TPE session in 2018 and 2020, the total number of sessions, the total number of teachings, and the mean number of sessions per child. The number of children who had at least one TPE session was stable (around 45 per year) over the period. However, the number of sessions increased considerably in 2020, with a total of 35 sessions, including 24 online (compared to 18 sessions in 2018, not on line). The total number of teachings increased from 61 in 2018 to 71 in 2020. The mean number of sessions per child (individually or in 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. A majority of children that 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. Age distribution did not change significantly between 2018 and 2020 with 40-45% of participants aged 6-10 years; one third aged 10-14 years, and 20-26% aged 14 years and older.

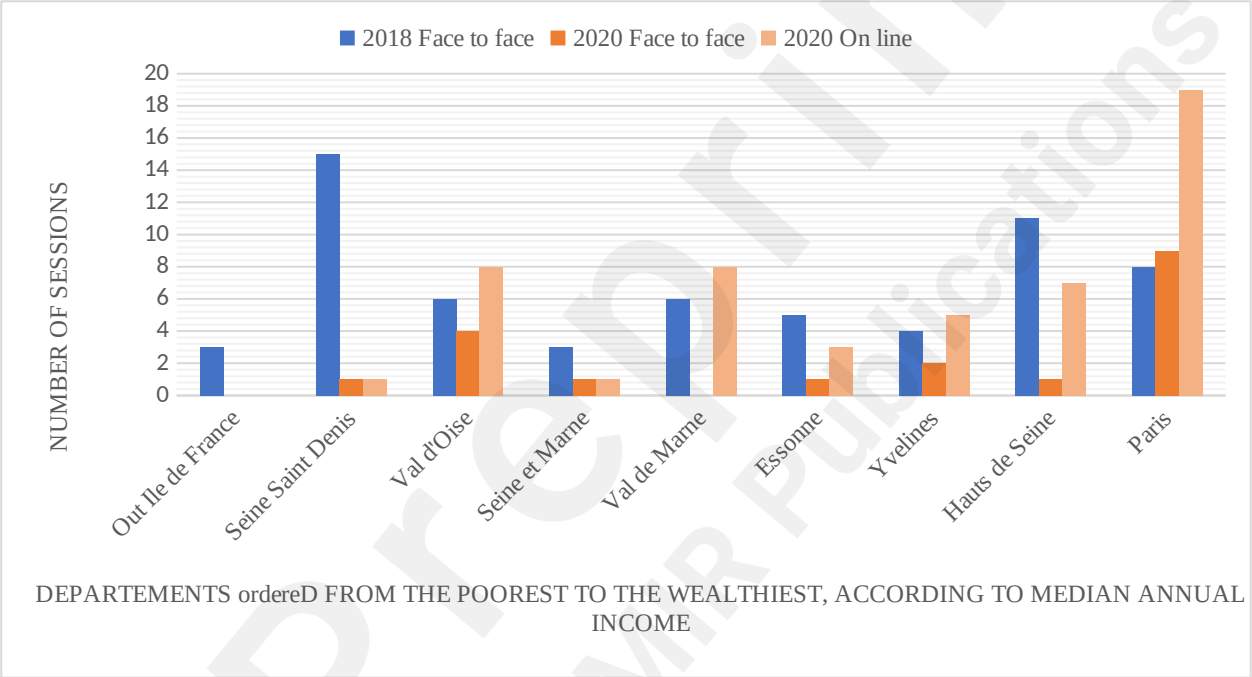
Participation varied greatly according to the geographical area of residence, with a major drop from 22.4% to 4.9% of attendees living in Seine saint Denis, one of the most socio-economically deprived French departments, contrasting with an increased proportion of patients living in Paris and Hauts de Seine, two of the most favoured French departments (figure 1).

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) range	1.24 (0.52) 1-3	1.73 (1.60) 1-9	0.047*

* comparison between 2018 and 2020, using a Student t-test

Figure 1
Number of ETP sessions in 2018 and 2020, according to the departments



DISCUSSION

SCD is a chronic disease that predominantly affects African or other racial minority or migrant population groups [3, 12]. Quality of life, life expectancy, and lifetime income are decreased in patients with SCD compared with matched individual without SCD [13]. Self-care interventions enhancing self-efficacy, access to education, and social support have been developed, mostly in adolescents and young adults, including a growing number of eHealth intervention [14-19]. Being patient-centered has appeared to be a key element for self-management support tools [16]. TPE is specifically a patient-centered learning tool of great interest for patients with chronic disease and its applications are increasing. While SCD was not mentioned by the WHO report in 1997, which listed only hemophilia and thalassemia in the group of blood disorders which could benefit from TPE [8], SCD children are now recognized as good candidates for TPE.

Our study did not aim to evaluate the effectiveness of TPE in children with SCD, since there was no control group, but it aimed to assess the feasibility of continuing TPE during the COVID pandemic. Interestingly, we observed that providing sessions online was associated with an increase in the total number of trainings. However, the participation to online sessions appeared to be easier for children

and families living in departments with higher incomes. In these departments, TPE was attractive enough to encourage children to attend more sessions. We hypothesized that the increased participation to TPE was associated with the fact that families were confined at home, could participate without the burden of transport, and had the possibility 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 surely, and probably also 11-14 years), the application was initially driven by the parents, but it appeared soon that children were at least as confident as their parents to use the application. The high level of stress related to the COVID-19 pandemic has likely contributed to the interest in online discussions, and the RoFSED developed over the same period psychological support, enabling children and families to communicate their fears and questions. Interestingly, the increase in the number of sessions was the consequence of an increase in the number of individual trainings, while the number of group sessions did not change, which may be related to worrying about being in group after the pandemic onset.
The fact that families living in the most socio-economically deprived French department had less use of TPE may have several explanations. For online sessions, a poorer access to internet and more difficulty using the application are possible causes. For face-to-face sessions, families living in more overcrowded conditions may have experienced fears related to COVID-19 infection and hesitation to use public transports. Whatever the causes, socioeconomic deprivation appears as a risk factor for lower access to information and self-care knowledge. Poverty in children with SCD has previously been shown to be associated not only with lower quality of life, but also with higher pain burden and healthcare utilization [20-22]. COVID-19 infection appears to amplify the disparities in health care providing for socio-economically deprived children with SCD.

Our study has several limitations, such as a single center recruitment and a small simple size. We did not assess individual socio-economic characteristics and parental education levels. Also, we did not evaluate the efficacy of our TPE program.

The COVID-19 pandemic has brought an urgent need to enhance digital approaches [23]. Our findings show that patients and families may find interest in these tools which could facilitate patients' daily life. However, there is most likely unequal access to these interventions, with the risk of enhancing the pre-existing social disparities [24]. There is need for future research, in particular on the assessment of the safety and efficacy of these tools in SCD, and on the possibility to offer them equally to all patients and families.

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

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AUTHOR CONTRIBUTIONS
AS, MdM, and SA designed the study, interpretated the results, and wrote the manuscript.
AS, SM, MV, AL, and LP performed the TPE teachings.
MdM, MT, and SA adressed the children.