International Journal of Public Health Science (IJPHS)
Vol. 12, No. 1, March 2023, pp. 239~251
ISSN: 2252-8806, DOI: 10.11591/ijphs.v12i1.21940

Lessons learned from COVID-19 impact of pandemic on children with neurological disorders in Sfax, Tunisia

Salma Zouari Mallouli[1], Sahar Najjar[2], Fatma Kamoun Feki[1], Olfa Jallouli[1], Sihem Ben Nsir[1], Wafa Bouchaala[1], Mathilde Leonardi[3], Chahnez Charfi Triki[1]
[1]Child Neurology Department, Hedi Chaker Sfax University Hospital and Research laboratory LR19ES15, University of Sfax, Sfax, Tunisia
[2]Psychiatry Department, Hedi Chaker Sfax University Hospital, University of Sfax, Tunisia
[3]Public Health, Disability Unit, Fondazione IRCCS Istituto Neurologico Carlo Besta, Milan, Italy

Article Info

Article history:

Received Apr 3, 2022
Revised Nov 2, 2022
Accepted Nov 19, 2022

Keywords:

Access to healthcare
Caregivers
COVID19
Health policy
Lockdown periods

ABSTRACT

To record the experience of caregivers for neurologically impaired children during the lockdown periods. Data from 286 children's caregivers were collected through an administered questionnaire to record: access to care services during the lockdown periods, causes underlying loss of access to care, mitigations adopted by caregivers and patients' outcomes. The mean age of children was 8.11 years-old and sex ratio (F/M) was 0.66. They were mainly followed-up for epilepsy or epileptic encephalopathy (53%) and cerebral palsy (21%). During the lockdown periods, caregivers reported that 45% of children had no access to healthcare majorly for neurorehabilitation (76.7%) and medicines (70.7%). Most caregivers (36%) related limitations in access to fear from catching the virus. The majority resorted to continuation of the same treatment via primary healthcare facilities (41%) and postponement of their appointments (24%). Our results show that access to healthcare for children with neurological disorders was deeply disrupted during the COVID-19 pandemic. The already precarious health systems' infrastructures might have been the main causes for this and should be thus considered in the health policy and planing.

Corresponding Author:

Salma Zouari Mallouli
Child Neurology Department, Hedi Chaker Sfax University Hospital Tunisia and Research laboratory LR19ES15-Sfax University
Tunisia
Email: mallouli.salma26@gmail.com

1. INTRODUCTION

Healthcare system in Tunisia relies on two independent sectors, public and private sectors both under the dependence of the ministry of health. However, the distribution of material and human resources is inequitable between both sectors. The public health system financed from taxation run by the national health insurance Fund. It includes health centers providing primary care, district and regional hospitals, and university hospitals and ensures care for the majority of the population. The private health sector is concentrated in the cities and possesses 23.6% of the total bed capacity, 75% of the top range medical equipment, more than half the doctors (54%) and pharmacies (84.8%). This imbalanced resource supply makes the healthcare system a fragile structure whenever there is a health crisis [1], [2]. Since the beginning of the COVID-19 pandemic, several lockdowns were necessary, always depending on the levels of the pandemic situation. Tunisia experienced two main pandemic waves. The first spread from January to July 2020. The second one started around August 2021 and continued until the time of the study. Meanwhile, Tunisians experienced two full lockdown periods: the first lasted from March 22, 2020 to April 20, 2020 and the other from January 14-24, 2021. In the meantime, several levels of curfews and restrictive measures were necessary depending on the stage of disease transmission [3]. Although such policy was aimed to limit the spread of infection and protect the integrity of people, lack of awareness of associated measures necessary to overcome the pandemic crisis led to a huge bankruptcy in the care structures. Thus, besides affecting global population health, the outbreak of COVID-19 pandemic has also deeply affected access to healthcare services and led to several changes in daily clinical practice [4], [5]. There are several reports on effects of disruptions of health care services for patients with chronic disease, and children with neurological conditions were particularly exposed to both this life-threatening situation as well as to its consequences on health care delivery [6]–[9].

In the specific disabled pediatric population, health policies such as full lockdown, services and school closure as well combined with fear of catching the virus, played a double-sided coin for this vulnerable population. On one hand, lockdown measures such as strict isolation and prevention allowed these children, usually carrying several comorbidities including respiratory problems, to avoid being infected [9]. On the other hand, safety measures prevented most of those children from getting the appropriate medical care and support prompting worsening of their condition and increasing the risk of developing complications [10]. Since the start of the pandemic, several articles have presented and discussed the problems of continuity of care for neurological pathologies in children and adults. These studies are mostly reporting the causes of services' disruptions and the means of their mitigation from the point of view of health professionals or scientific and patients' associations [4]–[6], [11].

The COVID-19 pandemic led to a stalemate and its impact will continue throughout 2021 to 2022 [12]. Hence, recent studies are now directed to the government's work to help the system recover and retrieve efficient functioning as the immediate emergency response phase decreases and vaccination rates increase over time [12]–[14]. Although data showed increased pediatric COVID-19 cases and hospitalizations in some low and middle income countries as tshwane district in South Africa and Tunisia in North Africa; trials to establish future plans to restore care delivery are sparse [15], [16]. The current study, we focused on reporting the effects of healthcare disruptions from caregivers' perspectives and the mitigation strategies they adopted. Awareness of these new data about caregiver's constraints to access to care allowed us to study the dynamism between the healthcare sector and other vital sectors compulsory for its functioning. Based on this data, we were able to propose a resilience strategy to promote continuity of care delivery in subsequent upcoming waves. The aimed of this study was to estimate the impact of healthcare access' limitation among children with different neurological conditions, in order to identify the causes of service disruption, the effects on children of these disruptions, and to unravel mitigation strategies adopted by caregivers and finally to try to evaluate patients' outcome.

2. RESEARCH METHOD

We carried out a cross-sectional survey study. A structured protocol with questionnaire purposely defined was proposed. Responses were obtained from caregivers of children with neurological conditions during face-to-face follow-up visits.

2.1. Study participants

Between March 15, 2021 and May 31, 2021, all caregivers of children with chronic neurological disorders monitored by the Child Neurology Department of Sfax University Hospital were invited to freely answer a structured questionnaire purposely defined. We considered caregivers: parents, mothers and anyone who takes care of children. Before questionnaire administration, consent was obtained by each participant and collected by a single author (Dr N. S.) in respect for the anonymity of the participants. Children with a variety of neurology conditions and their caregivers were encouraged to participate in the inquiry. According to their neurological condition, patients were assigned to five groups as follows: Epilepsy, epileptic encephalopathy (EE), cerebral palsy (CP), neuromuscular diseases (NMD), and other neurological conditions. The inclusion criteria were: to obtain the informed oral consent of the caregivers, to be followed in the pediatric neurology department for a neurological pathology before the lockdown of March 22, 2020, to be able to speak, read and write in Arabic. We excluded former patients who had irregular follow-up in the department. A distance of 11 km from the city center delimiting the community area where public transport is accessible was used as an end point to specify the patients' location inside (<11 km) or outside Sfax (>11 km).

2.2. The global child survey questionnaire

The survey questions were developed taking into account the healthcare system and neurological services available in Tunisia, before the emergence of the COVID-19 pandemic. Although we do not have a detailed report of neurological health services in Tunisia, however data from the WHO Atlas provide us with some informations like lack of neurologists in the urban region outside the capital city and rural regions as well as anticonvulsant availability at primary care and hospital level [17]. The survey was designed to assess caregivers' insight on access to different healthcare services, reasons for loss of access to care and their approach faced with barriers to access healthcare during the pandemic. Questions screened the following 7 main items: i) demographic data, ii) neurological condition, iii) cervices types, iv) causes of limitation in access to healthcare services, v) mitigations adopted by caregivers of patients, vi) mitigations adopted by healthcare professionals, vii) patients' outcomes evaluation. These items are more detailed in Table 1.

Table 1. The table shows mains sections and items of the global survey questionnaire

Survey items	Items content
A. Demographic data	Age, Gender Origin: 1. Sfax: < 11 Km 2. Outside Sfax: > 11 Km
B. Neurological condition	1. Epilepsy 2. Epileptic encephalopathy 3. Cerebral Palsy 4. NMD: Myopathy, Myasthenia, Neuropathy, Guillain Barre syndrome, Spinal muscular atrophy 5. Others: vascular, infectious, inflammatory diseases
C. Services types	1. Primary healthcare (PHC) facilities 2. Emergency 3. Outpatients services 4. Inpatients services 5. Investigations : (a) Laboratory analysis (b) Radiology exams (c) Neurophysiology exams (PEV/EMG) (d) Electroencephalogram (EEG) 6. Drugs availability 7. Neurorehabilitation 8. Interventions: Botulinum toxin injections 9. Orthopedic surgery 9. Patients' associations 10. Scolarity
D. Causes of limitation in access to healthcare services	1. Transport problems 2. Fear of becoming infected 3. Financial problems 4. Services closure 5. Personal insufficiency 6. Drugs out of stock 7. Unavailability of drugs 8. No nearby emergency 9. Others
E. Mitigations adopted by caregivers of patients	1. Appointment report 2. Switch of appointments from public to private sector 3. Continue same treatment via pharmacy or dispensary 4. Bring the treatment from other countries 5. Drug stock before containment /reduce doses 6. Self-reeducation / Auto-medication 7. Nothing (follow-up discontinuation)
F. Mitigations adopted by healthcare professionals	1. Telemedicine + Tele rehabilitation 2. Molecule substitution
G. Patients' outcomes evaluation	1. Adherence to treatment 2. Outcome according to caregivers: (a) Worsening (b) Improvement (c) Stable

2.3. Analysis

Data was analyzed using statistical package for social science version 20 (SPSS 20). Qualitative variables were represented with frequencies. Hence, quantitative variables were reported with means and standard deviation.

3. RESULTS AND DISCUSSION

3.1. Demographic data

Our survey on access to care of children with neurological conditions during COVID 19 pandemic collected data on 286 patients. The mean age was 8.11 years-old, while sex ratio (F/M) was 0.66. The majority (83%) of children' caregivers that replied to the survey were their mothers. Moreover, 42% of children were from Sfax city and 58% were coming from the peripheral areas of Sfax or other governorates.

Within children, 35% were treated for Epilepsy, 18% for EE, 21% for CP, 8% for NMD, and 18% for other neurological diseases as shown in Table 1. For children with epilepsy and EE, drug resistant epilepsy was observed in 33% of cases. They all needed daily anti-seizure medications (ASMs). Children with EE need regular neurorehabilitation in addition to electroencephalogram (EEG) monitoring and ASMs. Management of children with CP, or NMD and other neurological diseases required neurorehabilitation and interventions such as botulinum toxin injection and orthopedic surgery.

3.2. Access to associations and schools

Almost a third (29.7%) of children were going to school, and a fifth (17%) were enrolled in a patient association. Among them, 95% dropped out of school. Hence, none of the children had access to his association during the periods of lockdown.

3.3. Access to healthcare services

Nearly half of caregivers (45%) answered that their children during the lockdown periods did not have access to different healthcare services when needed. In general, this statement was mainly made for neurorehabilitation (76.7%), medicines availability (70.7%), interventions such as botulinum toxin injection (57.1%), outpatient services (53.8%) and orthopedic surgery (42.8%). The details are presented in Figure 1.

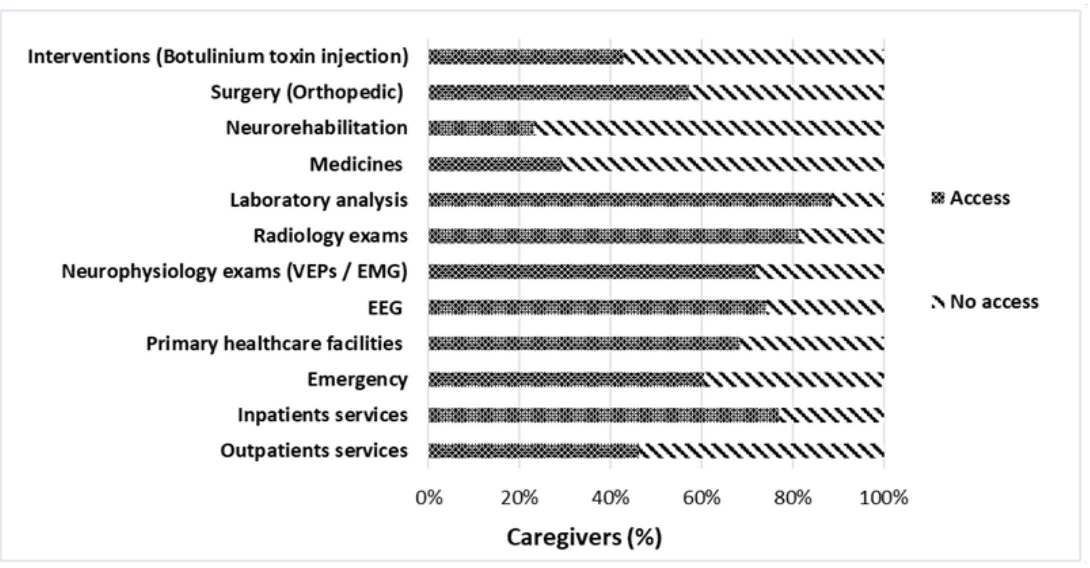
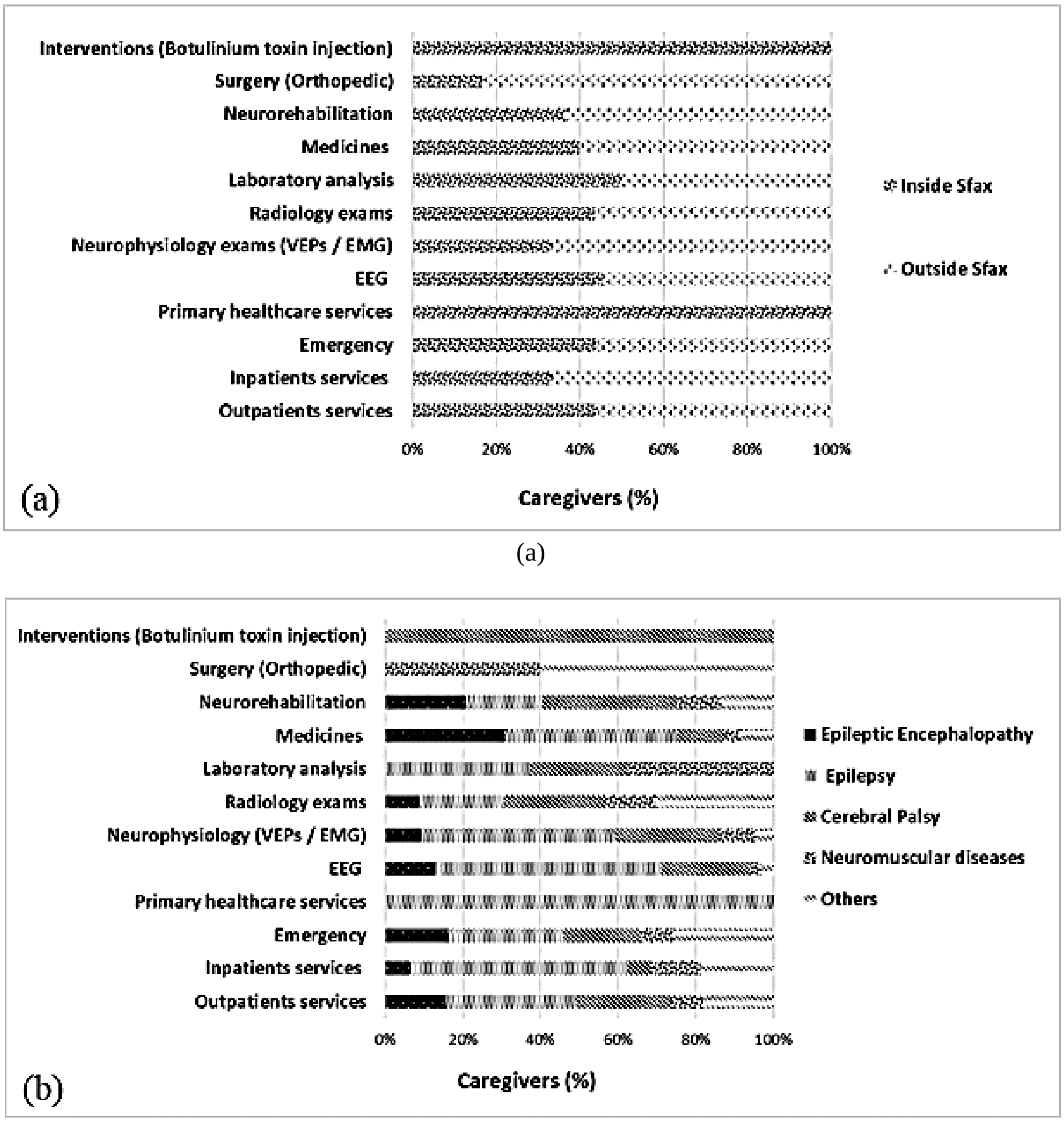


Figure 1. The figure shows the percentages of caregivers reporting access to healthcare with respect to different services

We noted discrepancies in terms of limitation in access to healthcare according to patients' location and to different neurological diagnosis and conditions. Indeed, the majority of caregivers who claimed alteration in access to different healthcare services (59%) came from outside Sfax (peripheral zones and other governorates) as shown in Figure 2(a). Likewise, there was variability in access to different types of services depending on the patient's disease. For example, caregivers of patients with epilepsy more often reported limited access to primary health care (PHC) facilities (100%), planned hospital admission (56.2%) and EEG (54.7%). In contrast, caregivers of patients with EE complained of lack of access to ASMs (30.9%) and neurorehabilitation (20.7%). Those taking care of children with CP suffered mostly from cancellation of planned interventions such as botulinum toxin injection (100%) but also from limited access to neurorehabilitation (34.2%). NMD patients were associated with limited access to orthopedic surgery (40%) as well as to laboratory analysis (37.5%) as presented Figure 2(b).



(a)

(b)

Figure 2. The figure shows the percentages of caregivers reporting limited access to different healthcare services. The panel (a) shows limited access with respect to caregivers'origin. The panel (b) shows limited access with respect to children neurogical condition

3.4. Causes of limitation in access to healthcare

Most respondents explained limitations in access to healthcare due to fear of catching the virus (36%), to health services' closure (19%) and due to drugs out of stock (17%). Other causes included the lack of medical and paramedical personnel, due to self-isolation of those infected or to their reorientation towards COVID-19-unit care (8%); some caregivers reported financial problems of families (7%) or difficulty of transport (6%).

According to the type of services, caregivers reported differences in distribution due to several reasons. For example, transports' problems were reported as being one of the main reasons for cancellation of planned hospital admission (27.7%). Fear of becoming infected was the major cause behind emergency (88%) and outpatient services (55.7%) avoidance. Financial problems were the cause of the limitation of access to investigations such as laboratory analysis (63.6%), neurophysiology (28%) and radiology (26%) examinations requested. Others that were needing interventions like botulinum toxin injection or surgery and those depending on PHC facilities, mainly complained of service closure in 75%, 33.3%, and 55.3% respectively. Finally, caregivers whose children needed neurorehabilitation (29.4%) or EEG recording (30.3%) mostly complained for the lack of healthcare providers as shown in Figure 3.

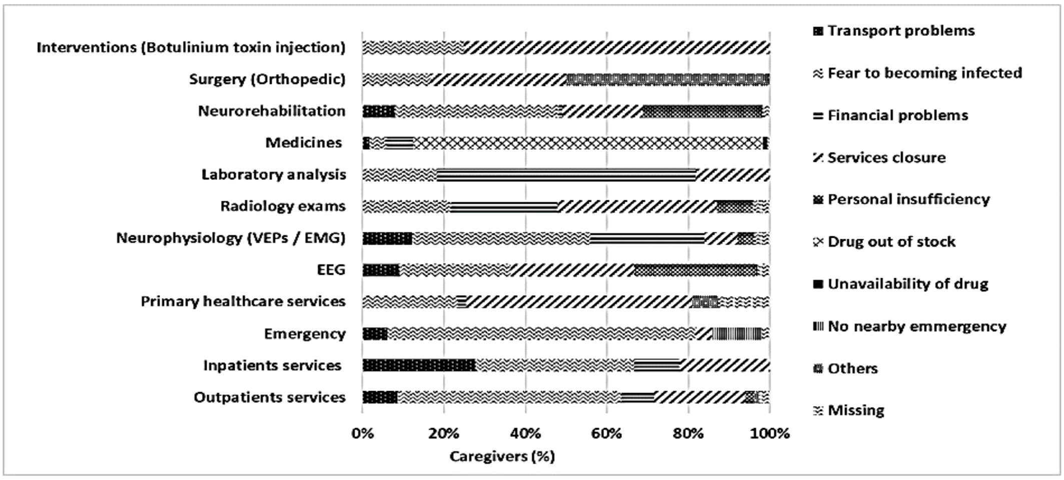


Figure 3. The figure shows the percentages of caregivers reporting causes of limitation in healthcare access with respect to different services

There was also variability in causes stated by caregivers with different geographic locations and with children with different neurological conditions to explain barriers found to access healthcare. In fact, caregivers living inside Sfax mostly reported limited access to healthcare due to fear of becoming infected (46.4%). For those coming from outside Sfax, fear of becoming infected accounted only for 27.8% of causes to explain limited access to healthcare. Other causes included services closure (23.6%), financial (11.4%) and transport problems (8.6%) as shown in Figure 4(a).

Fear of becoming infected was the major cause behind limited access to healthcare regardless of the children's neurological conditions or severity of the disease. Other causes varied according to the patients' neurological condition. Indeed, causes were dominated by drug shortages (22.6%) for patients with epilepsy and rather by services closure (28.5%) in addition to lack of healthcare providers (9%) for non-epileptic patients as presented in Figure 4(b).

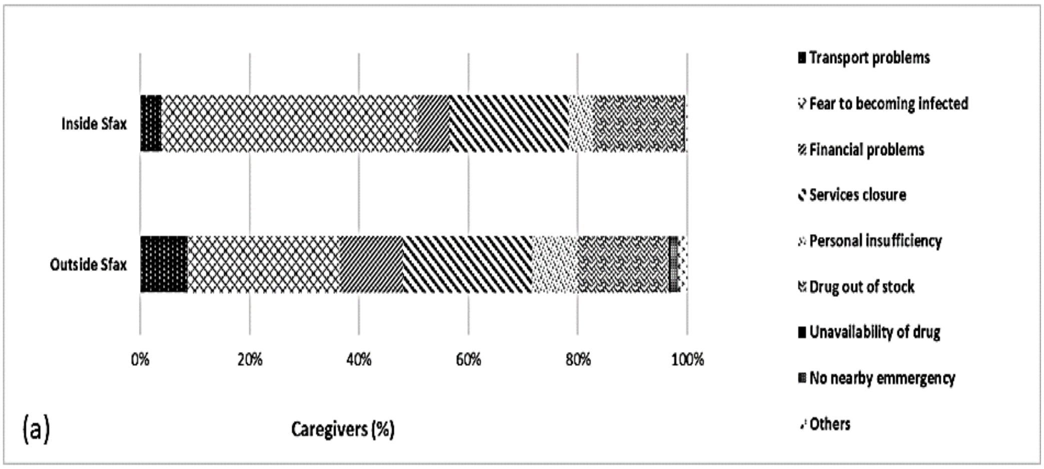
3.5. Mitigation strategies

Caregivers of children with neurological disorders adopted several mitigation strategies to overcome their loss of access to health services. The most prevalent strategy was the continuation of the same treatment delivered through PHC or private pharmacies as did 42% of the whole population of the study and 21% of patients coming from inside Sfax. The postponement of outpatient or neurophysiological exams appointments was the second leading solution adopted by 24% of the whole population study and 29% of patients coming from outside Sfax. Remote and virtual care was limited to a minority of patients who had reliable internet networks and hardware so they could benefit from telemedicine (1%) or Tele Neurorehabilitation (1%) as shown in Figure 5. To overcome transportation problems during the lockdown periods, patients mostly counted on private transport means like taxis and authorized rental cars (56%). In parallel, there has been an avoidance of public transport inadequate to guarantee physical distancing. These changes were more marked in the peripheral regions (67% vs 48%). Caregivers of children with epilepsy first strategy was the appointments' postponement, adopted by 36% of caregivers of patients with EE and 23% of patients with epilepsy. As for the switch of care from the public to the private sector, it was the second option for patients with EE (21%). Delayed appointments mostly concerned Neurorehabilitation (82%), hospitalizations (55%) and EEG (28%). The private sector was mainly called upon to compensate for the unavailability of emergency care (55%).

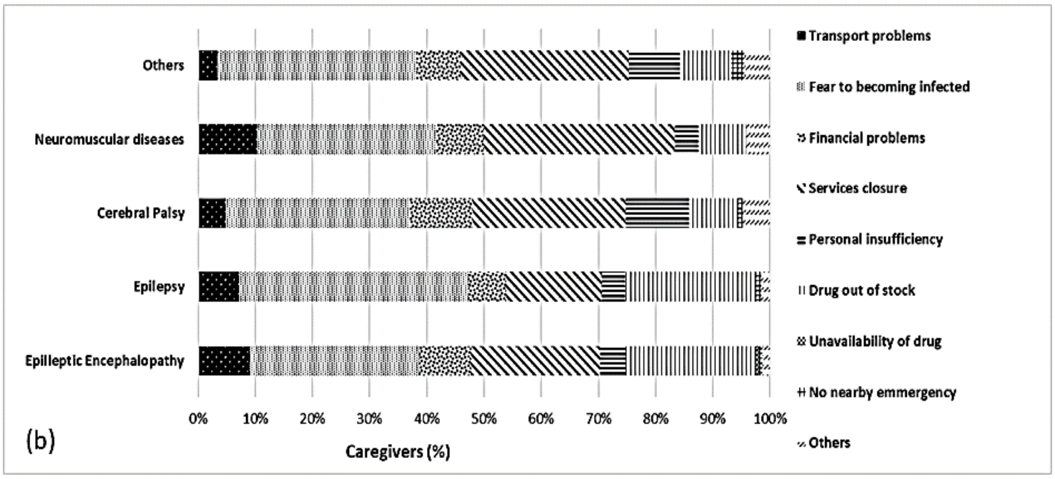
3.6. Patients' outcome

According to caregivers, limitation in access to healthcare led to non-compliance to treatment in 19% of patients and less frequently to discontinuation of medication (3%). This was associated with worsening of the underlying neurological condition in 23% of patients as shown in Table 2. It is of note that some conditions like CP (28%) and EE (25.4%) were particularly affected and associated with such an outcome. Both conditions largely rely on good rehabilitative care, which was one of the most affected services by the pandemic. In contrast, more children (44%) showed improvement during the lockdown periods with more caregivers present nearby their children and thus able to ensure compliance to medications

(44%) as presented in Table 2. Indeed, 49.4% of children with epilepsy and 43.4% of children with NMD showed better diseases' control during the lockdown period.



(a)



(b)

Figure 4. The figure shows the causes of limited access to healthcare. The panel (a) shows the causes according to childern's origin. The panel (b) shows the causes according to childern's neurogical conditions

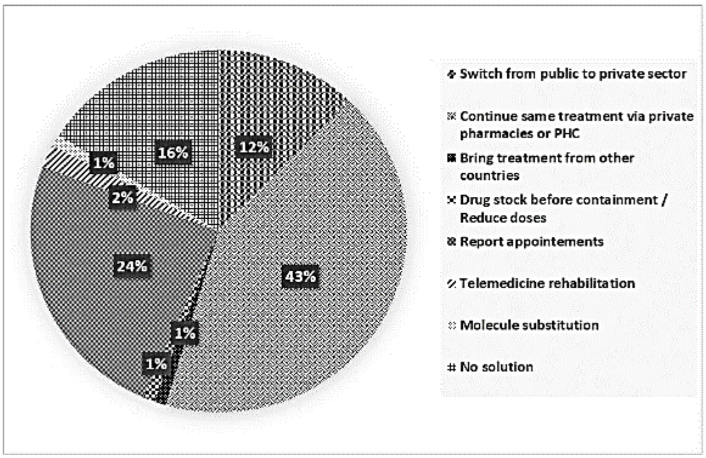


Figure 5. The figure shows the percentages of the different mitigation strategis adopted by caregivers during lockdown

Table 2. The table show disparities between studies reporting COVID-19 impact on healthcare delivery according to study design

	The present study		Marine Cacioppo, 2021 [8]	S. Jeste, 2020 [21]		Elaine C. Wirrell, 2020 [6]
	Whole population study	Only epileptic patients		USA	Outside USA	
Study design	A cross-sectional study		A cross-sectional study	A cross-sectional study		A cross sectional, online survey of world pediatric neurologists
	A survey questionnaire administred during face-to-face interview by Dr N. S		An online survey and following the STROBE guidelines. ECHO survey	An online survey distributed widely by the mighty and patient advocacy groups		
Study location	Nationwide/Sfax, Tunisia (Lower middle-income countries)		Nationwide/France (High income countries)	International/USA/Outside USA (Mostly from High income countries)		Worldwide/6 continents (all income bank)
Respondents	caregivers of children with physical disabilities		caregivers of children with physical disabilities	caregivers of individuals with Intellectual disabilities		Pediatric neurologists
Population size	286	152	1,000	1,106		212
Studied pathologies (%)						
1. Epilepsy	35	65.8	0	57	53.7	100
2. EE	18	34.2	0	NA	NA	0
3. Cerebral palsy	21	0	42	NA	NA	0
4. Neuromuscular diseases	8	0	11	NA	NA	0
5. Others	18	0	6	NA	NA	0
Services disruption (%)						
1. Emergency	40	15	NA	NA	NA	NA
2. Outpatient services	53.8	50	NA	65.1	70.7	91.5
3. EEG	25.7	14.5	NA	NA	NA	90.6
4. Medicines	70.7	62.5	NA	NA	NA	NA
5. Neurorehabilitation	76.7	29.6	45	60	84%	NA
6. Intervention thearpy	57.1	0	NA	NA	NA	NA
7. Surgery	42.8	0	NA	NA	NA	NA
Schooling (%)						
1. School discontinuation	95	NA	21	43.2	66.3	NA
Outcome (%)						
1. Improvement	44	44	NA	NA	NA	NA
2. Worsening	23	15	8	NA	NA	NA
3. Stable	33	31.5	47	NA	NA	NA

NA: data not available

3.7. Discussion

Here we reported the first Tunisian survey during the pandemic COVID-19. This survey was intended to assess caregiver's standpoint about access to health care, their constraints and their approach faced with the collapse of essential health sectors resulting from governmental containment policy done in order to limit the pandemic spread. Since the pandemic outbreak and until nowadays, data on COVID-19 impact on healthcare delivery for individuals with neurological disorders came mostly from high income countries, from single countries and multiple counties studies [4], [5], [11]. According to another report recording data from the Eastern Mediterranean Region, investment in young peoples' mental health is extremely limited and could be critical in the post-COVID-19 era [13].

Collected data differed whether participants were clinicians or patients and their caregivers. In addition, most publications assessing neurological services delivery concerning children focused on epilepsy management during the pandemic while fewer studies looked at the situation on other neurological disorders [5]. Other considerations are as substantial as the previous ones when analyzing the data already published like age range and the neurological condition of the studied populations, healthcare system structure and services already available in the country where the study was carried out as well as the disease transmission stage in the region and the category of income bank as shown in Table 1. These issues were a source of mismatch to make a valid comparison of the pandemic effect on different countries at a fixed time. The problem is multidimensional and a real representation of the situation cannot be established without having a view of the different aspects. There is henceforth a need to consider country/region-limited studies to address the particular aspects of the pandemic in these areas.

In this perspective the current study provides data about access to healthcare during several lockdown periods according to caregivers of disabled children with various neurological conditions. We particularly tried to address if there is a correlation between the neurological conditions and different affected services and whether some diseases were more affected by the pandemic. We also looked for differences in access to healthcare according to caregivers' geographical location.

During the present survey, almost half of caregivers (45%) responded that their children did not have access to various healthcare services when needed. They mostly complained about reduced access to neurorehabilitation (76.7%) and unavailability of medicines (70.7%). A recent review related medication shortages during COVID-19 pandemic to the shift of pharmaceutical manufacturers to producing medical equipment and pharmaceutical preparations to fight against COVID-19 in addition to difficulties in medication distributions owing to lockdown measures [18]. Cross-sectorial services -represented by patient's associations in our study design- showed the highest rate of caregivers (100%) reporting loss of access due to complete closure. Nonetheless, these services were already deficient before the pandemic outbreak and only 17% of our population-study benefited from them. The other disabled children had no access for geographic and economic considerations in addition to lack of parent awareness. Indeed, there are specialized centers dedicated solely to the charge of the handicapped population in Tunisia. These centers fall under the tutelage of the ministry for social affairs. UNICEF reports that in 2007 as many as 14.5% disabled children frequented these centers [19]. As shown in our results, numerous papers described the deleterious impact of the lack of access to medical care among these vulnerable children with disabilities and special needs [6], [9], [20].

Another international survey -assessing changes in access of caregivers for children with disability to educational and healthcare services- found that 76% of participants lost access to at least one therapy or educational services and 53% were unable to see at least one of their healthcare providers when needed during this pandemic period [21]. Differently, a recent global survey recording the overview of global international neurological patients and scientific associations during COVID-19 reported cross sectorial neurological services as the most affected services (57%) followed by neurorehabilitation (56%) [4]. Differences could be explained by different study design regarding participants, services' types included and already available interventions for the management of neurologically impaired children in the studied population. Indeed, neurological diseases are generally chronic disabling conditions that require some accommodations of the patient's environment and a lifelong monitoring done by a multidisciplinary team including continuous nursing, specialized neurorehabilitation, lifelong medical and interventional treatment as well as regular follow-up. Moreover, the management of these debilitating conditions directly involves children's parents and caregivers. Thus, this vulnerable and fragile population was particularly at risk of worsening the underlying neurological condition, faced with the lack of access to care and with the caregivers' strategies to overcome this during the COVID-19 pandemic [9]. Indeed, some neurological conditions damage the respiratory system and sometimes require corticosteroids or immunosuppressive use harmful for the immune system. These reasons made the current severe acute respiratory syndrome related to coronavirus (SARS-CoV 2) a life-threatening circumstance for several neurologically impaired children. Taken together, all this evidence suggests that very strict isolation and prevention measures are appropriate in children with chronic neurological diseases. However, it must also be noted that obviously such measures limited access to primary care and neurorehabilitation services resulting in worsening of children's neurological state and favoring the occurrence of complications from the preexisting conditions [6], [22], [23]. This deleterious outcome concerned 23% of our population and ranged from 11% to 30% in the literature [9]. During the lockdown periods, patients' associations closure set up by government policies led to lifestyle changes in all patients with disability. Assessing the impact of this conduct was not concluding as only a minority of our population (17%) benefited from this service before the pandemic. Indeed, caregivers for children with neurodevelopmental problems were complaining about restriction of activities and exercises necessary to improve skills of this fragile young population [10].

In literature, it is reported that far from the supervision of their teachers and healthcare workers, children also run the risk of abuse and neglect of frustrated parents due to fear of illness, working from home while caring for children, financial insecurity and lack of free time outdoors [24], [25]. Studies carried out among children and adolescents with other neurological conditions such as primary headaches, however, found a correlation between patients' condition improvement and school discontinuation. The authors explained such a finding by reduction in school-related stress [26], [27]. Others, however, thought the lockdown was beneficial for children and their caregivers. Indeed, the caregivers -being with their children round the clock- were more able to provide them adequate care and support than ever [9]. This hypothesis may explain the important rate of caregivers who reported improvement of their children's neurological state during the lockdown period in the present study.

Limitation in access to healthcare services showed inequity depending on children's location, as loss of access to care concerned mostly those living outside Sfax (59%). Such a finding was widely reported by numerous papers [6], [28], [29]. Deployment of mobile care facilities and doorstep delivery of essential drugs could have made it possible to restore healthcare delivery in isolated and/or severely disabled individuals lacking efficient public transport and reliable internet network and thus unable to access healthcare by any other means. Difficulties in mobility and transportation do not mean only having efficient transport by cars vehicles but also relate to conditions of streets and of train and bus stations to facilitate access of caregivers carrying their children on wheelchairs for example children with different neurological conditions did not have similar changes in access to care services.

As our population study included mostly children with epilepsy (53% of whom 35% with epilepsy and 18% with epileptic encephalopathy), more attention has been paid to this group. Caregivers of epileptic patients mostly reported limited access to primary health care facilities (100%) and to planned hospital admission (56.2%) where beds were limited due to deployment of a part of the department to COVID-19 management, despite such measures had been contradictory to the international pediatric association's (IPA) recommendations for preservation and prioritizing of primary care and hospital resources for children during the current COVID-19 pandemic [30]. In a second place, caregivers of patients with epilepsy complained of the reduced access to EEG and of medicines shortages. Limitation in access to both services was previously stated and accused of being behind seizure worsening and a prevalent impediment to epilepsy management [6], [31]–[33]. COVID-19 pandemic imposed drastic measures, including border shutdowns, which led to disruption of drug-ingredients' supply chains, production, storage and distribution of medications. The halt of expiring insurance renewal and drugs reimbursement procedures, loss of employment and financial issues among caregivers increased the constraint of drug shortages [21], [33]. On this issue, a recent paper gave a proposal for a framework to guarantee epilepsy control during an epidemic at different levels [31]. Such an approach should have been developed and applied in order to restore drug supply. Elsewhere, monitoring of children with uncontrolled epilepsy could have been ensured thanks to ambulatory EEG if it was available.

Caregivers accused several reasons of being responsible for reduced access to different healthcare services. Fear from becoming infected was the leading cause underlying loss of access to care among caregivers from inside Sfax, those living outside Sfax complained of additional constraints like services closure, transport and financial problems. Our findings were consistent with a previous review carried among a pediatric population where all parents attributed their avoidance of accessing hospital to fear from catching COVID-19 virus. This review also recorded the overview of clinicians who were persuaded the main cause for reduction in access to emergency care or to PHC was rather government's directives like services closure and drugs out of stock [10].

Regarding mitigation strategies, our findings highlighted that proximity of PHC services has proven to be effective in times of pandemic. However, these alternate care sites are still sparse especially in rural areas compared to urban areas as shown by our results. Since 1978, the World Health Organization (WHO) added the PHC to the agenda as a basic health care accessible for all countries. Among the primary principles and basis of the Declaration of Alma Ata were: health as a human right, communities driving decisions that influence their health, healthcare close to where people live and coordinated efforts across society to create health, including fairer social and economic arrangements [34]. Unfortunately, in countries of all income levels, shifting care to PHC during COVID-19 as a strategy has been limited probably due to lack of health personnel and equipment and inadequacy of these care sites to apply safety measures such as physical distancing especially due to the growing number of referred outpatients. Elsewhere, most studies reported the growth of remote care, the so-called "Tele-neurology" or "Telemedicine" as the leading way to restore health care provision and maintain continuity of patient follow-up [4], [9], [35]–[38]. However, we should keep in mind that several key aspects of the neurologic examination as well as laboratory analysis for monitoring ASMs side effects could not be performed using remote care. Moreover, the pediatric population needs specific procedures requiring physical presence. Given technical hitches and poor access of patients to the internet, telemedicine is still limited in our country. In addition, teleconsultation was not possible via the phone because many of our patients' contact details were not updated in the Child Neurology services. Elsewhere, telemedicine can be a solution that allows supervision of children with chronic well-controlled conditions. Therefore, it should be promoted even in periods without COVID-19. Faced with this lack of a reliable communication tool, most caregivers from outside Sfax ended in postponement or discontinuation of care of their children.

The current study gave evidence not only of limitation of access to the healthcare systems during the pandemic but also highlighted according to caregivers of children with neurological conditions, some of the weakness of infrastructures, not only of health systems, but also transportation, internet connection, delivery of home care especially in remote areas. It provided useful data to define some priorities for the healthcare system's functioning and restoration by targeting the most vulnerable population like children with neurological conditions. It also helped to identify key components for the health of children that are not necessarily in the health sector such as pharmaceutical industry and drug supply, transport and internet networks. The main limitation of the present study is the lack of data on access to healthcare services in our country before the pandemic in order to quantify the real weight of the constraints generated by the pandemic on care access. The available data through the WHO Atlas are categorized by banc income level and WHO region and do not specify data by country [17]. In addition, our results may be biased by the relative frequency of different neurological conditions as most patients in our cohort study were children with epilepsy. Therefore, epilepsy seemed to be a more affected condition by the changes in daily care practice during COVID-19 pandemic.

4. CONCLUSION

This study furnished information that could help to organize a proposal for future scenarios and emergency plans in the setting of further sanitary crises such as during pandemics, natural disasters and wars so that bringing back better could not only be a motto but a reality. It provided a view on healthcare system weaknesses that should be the first target in order to improve health care delivery and to address equity in access to health services. A reflection on our results and on data from the literature led us to establish short and long-term recommendations in order to strengthen the care system and guarantee its accessibility for children with disability.

In the short term, there is a need to create delegations of inter-sectorial service coupled with each PHC. These delegations would have a mission: i) the recruitment of trained agents who ensure the education of parents and the training of caregivers and accompanying persons; ii) ensuring communication between the healthcare provider and the children association or school and iii) a regular update of the contact details of disabled and isolated patients and their needs. These delegations should be equipped with mobile care facilities and an efficient internet network to be able to be mobilized at the time of disasters and pandemics. In the long term, these delegations should have a common representative in charge of ensuring a coordination between governorate intervenants of various sectors like a bandmaster harmonizing a symphony between musical instrumentalists through: i) arrangement of public transport, educational and health structures to the physical condition of disabled children; ii) incorporating tele-medicine in daily routine clinical practice; iii) encouraging self-reliable and independent drug industry; and iv) adding secured software application to Google map facilitating access to the most isolated and the most severely disabled children.

REFERENCES

[1] A. Brayek, W. Gam, H. Dardour, S. Manai, “Démographie des professionnels de santé - Tunisie 2019”, [Online]. Available: http://www.santetunisie.rns.tn/images/statdep/DMOGRAPHIES-2019.pdf. (accessed Jan 1, 2022).

[2] A. Brayek, W. Gam, H. Ismail, S. Manai, “Carte Sanitaire Tunisie 2019”, [Online]. Available: http://www.santetunisie.rns.tn/images/statdep/Carte-sanitaire-2019-finale.pdf. (accessed Jan 1, 2022).

[3] M. Khadhraoui, “L'épidémie de Covid-19 en Tunisie en chiffres.” 2021, [Online]. Available: https://inkyfada.com/fr/2021/07/06/covid-19-dashboard-tunisie/. (accessed Jan 1, 2022).

[4] C. C. Triki *et al.*, “Global survey on disruption and mitigation of neurological services during COVID-19: the perspective of global international neurological patients and scientific associations,” *Journal of Neurology*, vol. 269, no. 1, pp. 26–38, Jan. 2022, doi: 10.1007/s00415-021-10641-3.

[5] D. García-Azorín *et al.*, “Disruptions of neurological services, its causes and mitigation strategies during COVID-19: a global review,” *Journal of Neurology*, vol. 268, no. 11, pp. 3947–3960, Nov. 2021, doi: 10.1007/s00415-021-10588-5.

[6] E. C. Wirrell *et al.*, “Care delivery for children with epilepsy during the COVID-19 pandemic: An international survey of clinicians,” *Journal of Child Neurology*, vol. 35, no. 13, pp. 924–933, Nov. 2020, doi: 10.1177/0883073820940189.

[7] J. M. Wilmshurst *et al.*, “Child neurology services in africa,” *Journal of Child Neurology*, vol. 26, no. 12, pp. 1555–1563, Dec. 2011, doi: 10.1177/0883073811420601.

[8] M. Cacioppo *et al.*, “Emerging health challenges for children with physical disabilities and their parents during the COVID-19 pandemic: The ECHO French survey,” *Annals of Physical and Rehabilitation Medicine*, vol. 64, no. 3, p. 101429, May 2021, doi: 10.1016/j.rehab.2020.08.001.

[9] S. M. Bova *et al.*, “Impact of COVID-19 lockdown in children with neurological disorders in Italy,” *Disability and Health Journal*, vol. 14, no. 2, p. 101053, Apr. 2021, doi: 10.1016/j.dhjo.2020.101053.

[10] S. Boronat, “Neurologic care of COVID-19 in children,” *Frontiers in Neurology*, vol. 11, Feb. 2021, doi: 10.3389/fneur.2020.613832.

[11] World Health Organization, “The impact of COVID-19 on mental, neurological and substance use services,” *WHO*, no. November. p. 49, 2020, [Online]. Available: https://www.who.int/publications/i/item/978924012455. (accessed Jan 1, 2022).

[12] G. B. D. of Health and C. Social, “Department of Health and Social Care outcome delivery plan: 2021 to 2022,” *GOV.UK*. 2021, [Online]. Available: https://www.gov.uk/government/publications/department-of-health-and-social-care-outcome-delivery-plan. (accessed Jan 1, 2022).

[13] J. Eaton, A. Rahman, R. Gater, S. Saxena, A. Hammerich, and K. Saeed, “From adversity to resilience in the COVID-19 era: strengthening mental health systems in the eastern mediterranean region,” *Eastern Mediterranean Health Journal*, vol. 26, no. 10, pp. 1148–1150, Oct. 2020, doi: 10.26719/2020.26.10.1148.

[14] T. Tam, “Release notice – The Chief Public Health Officer of Canada's Report on the State of Public Health in Canada 2020,” *Health Promotion and Chronic Disease Prevention in Canada*, vol. 41, no. 1, pp. 32–32, Jan. 2021, doi: 10.24095/hpcdp.41.1.06.

[15] E. Mziou *et al.*, “Bulletin de veille SARS_CoV-2-TunisieBulletin de veille SARS_CoV-2-Tunisie.” pp. 1–43, 2021, [Online]. Available: https://www.onmne.tn/wp-content/uploads/2021/10/Bulletin-de-veille-SARS-CoV-2-10102021-VFC.pdf. (accessed Jan 1, 2022).

[16] J. Cloete *et al.*, “Rapid rise in paediatric COVID-19 hospitalisations during the early stages of the omicron wave, Tshwane District, South Africa,” *medRxiv*, vol. 10. p. 18, 2021, doi: 10.1016/s2352-4642(22)00027-x CITATION MANAGER F.

[17] World Health Organization, “Atlas: country resources for neurological disorders - 2nd Ed,” *World Health Organization*. pp. 9–11, 2017, [Online]. Available: https://www.who.int/publications/i/item/9789241565509. (accessed Jan 1, 2022).

[18] W. T. Sze, S. Y. Huong, S. Y. Oon, I. Bin Zaharudie, and V. A. Sundaresen, “A literature review on the impact of COVID-19 pandemic towards patients living with chronic diseases,” *International Journal of Public Health Science (IJPHS)*, vol. 11, no. 3, pp. 1018–1028, Sep. 2022, doi: 10.11591/ijphs.v11i3.21167.

[19] K. Shaub, “Special Education in Tunisia: A Case Study in Social Entrepreneurship,” *Independent Study Project (ISP) Collection*. 2016, [Online]. Available: https://digitalcollections.sit.edu/isp_collection/2376/. (accessed Jan 1, 2022).

[20] S. Singh, D. Roy, K. Sinha, S. Parveen, G. Sharma, and G. Joshi, “Impact of COVID-19 and lockdown on mental health of children and adolescents: A narrative review with recommendations,” *Psychiatry Research*, vol. 293, p. 113429, Nov. 2020, doi:

10.1016/j.psychres.2020.113429.

[21] S. Jeste *et al.*, “Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions,” *Journal of Intellectual Disability Research*, vol. 64, no. 11, pp. 825–833, Nov. 2020, doi: 10.1111/jir.12776.

[22] K. Courtenay, “Covid-19: Challenges for people with intellectual disability,” *The BMJ*, vol. 369, p. m1609, Apr. 2020, doi: 10.1136/bmj.m1609.

[23] A. Lebrasseur *et al.*, “Impact of COVID-19 on people with physical disabilities: A rapid review,” *Disability and Health Journal*, vol. 14, no. 1, p. 101014, Jan. 2021, doi: 10.1016/j.dhjo.2020.101014.

[24] L. Cluver *et al.*, “Parenting in a time of COVID-19,” *The Lancet*, vol. 395, no. 10231, p. e64, Apr. 2020, doi: 10.1016/S0140-6736(20)30736-4.

[25] S. M. Brown, J. R. Doom, S. Lechuga-Peña, S. E. Watamura, and T. Koppels, “Stress and parenting during the global COVID-19 pandemic,” *Child Abuse and Neglect*, vol. 110, p. 104699, Dec. 2020, doi: 10.1016/j.chiabu.2020.104699.

[26] L. Papetti *et al.*, “I stay at home with headache. A survey to investigate how the lockdown for COVID-19 impacted on headache in Italian children,” *Cephalalgia*, vol. 40, no. 13, pp. 1459–1473, Nov. 2020, doi: 10.1177/0333102420965139.

[27] G. Dallavalle, E. Pezzotti, L. Provenzi, F. Toni, A. Carpani, and R. Borgatti, “Migraine symptoms improvement during the COVID-19 lockdown in a cohort of children and adolescents,” *Frontiers in Neurology*, vol. 11, Oct. 2020, doi: 10.3389/fneur.2020.579047.

[28] S. Bhaskar, A. Rastogi, K. V. Menon, B. Kunheri, S. Balakrishnan, and J. Howick, “Call for action to address equity and justice divide during COVID-19,” *Frontiers in Psychiatry*, vol. 11, Dec. 2020, doi: 10.3389/fpsyt.2020.559905.

[29] S. Basu, “Non-communicable disease management in vulnerable patients during Covid-19,” *Indian Journal of Medical Ethics*, vol. V, no. 2, pp. 103–105, Apr. 2020, doi: 10.20529/IJME.2020.041.

[30] M. El-Shabrawi and F. Hassanin, “Infant and child health and healthcare before and after COVID-19 pandemic: will it be the same ever?,” *Egyptian Pediatric Association Gazette*, vol. 68, no. 1, p. 25, Dec. 2020, doi: 10.1186/s43054-020-00039-7.

[31] D. Chen *et al.*, “Epilepsy control during an epidemic: Emerging approaches and a new management framework,” *Acta Epileptologica*, vol. 2, no. 1, p. 6, Dec. 2020, doi: 10.1186/s42494-020-00015-z.

[32] J. L. Rosengard *et al.*, “Seizure control, stress, and access to care during the COVID-19 pandemic in New York city: The patient perspective,” *Epilepsia*, vol. 62, no. 1, pp. 41–50, Jan. 2021, doi: 10.1111/epi.16779.

[33] D. V. F. Albert *et al.*, “The Impact of COVID-19 on epilepsy care: A survey of the American epilepsy society membership,” *Epilepsy Currents*, vol. 20, no. 5, pp. 316–324, Sep. 2020, doi: 10.1177/1535759720956994.

[34] K. Rasanathan and T. G. Evans, “Primary health care, the declaration of astana and COVID-19,” *Bulletin of the World Health Organization*, vol. 98, no. 11, pp. 801–808, Nov. 2020, doi: 10.2471/BLT.20.252932.

[35] D. Pareyson *et al.*, “Neuro-telehealth for fragile patients in a tertiary referral neurological institute during the COVID-19 pandemic in Milan, Lombardy,” *Neurological Sciences*, vol. 42, no. 7, pp. 2637–2644, Jul. 2021, doi: 10.1007/s10072-021-05252-9.

[36] M. C. McKenna *et al.*, “Patients’ experiences of remote neurology consultations during the COVID-19 pandemic,” *European Neurology*, vol. 83, no. 6, pp. 622–625, 2021, doi: 10.1159/000511900.

[37] S. Bhaskar *et al.*, “Telemedicine Across the Globe-Position Paper From the COVID-19 Pandemic Health System Resilience PROGRAM (REPROGRAM) International Consortium (Part 1),” *Frontiers in Public Health*, vol. 8, Oct. 2020, doi: 10.3389/fpubh.2020.556720.

[38] S. Bhaskar *et al.*, “Telemedicine as the new outpatient clinic gone digital: position paper from the pandemic health system resilience PROGRAM (REPROGRAM) International consortium (Part 2),” *Frontiers in Public Health*, vol. 8, Sep. 2020, doi: 10.3389/fpubh.2020.00410.

BIOGRAPHIES OF AUTHORS

Salma Zouari Mallouli is a Tunisian neurologist and paediatrician; a Hospital University Assistant at the Child Neurology Department of Hedi Chaker Sfax University. Member of “Neuropédiatrie” research laboratory (LR19ES15), University of Sfax. Interested in neuroinflamatory diseases, pain, epilepsy and neurodevelopmental disorders including neurocognitive and sensory-motor disturbances. Email: mallouli.salma26@gmail.com.

Sahar Najjar is a Tunisian psychiatrist trained in addictology and sexology who practices in an outpatient unit. Email: najjar.sahar88@gmail.com.

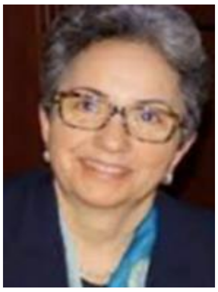
Fatma Kamoun Feki is a Tunisian neurologist and paediatrician. At present she is a Professor at Child Neurology Department of Hedi Chaker Sfax University Hospital. She is a member of "Neuropédiatrie" research laboratory (LR19ES15), University of Sfax. Member of "ICNA". ID 102063; EUREPA and "Formator on epileptology"; National League Against Epilepsy (ATLCE) as well as the European Paediatric Neurology Society (EPNS). Email: kammounfeki.fatma@gmail.com.

Olfa Jallouli is a Tunisian neurologist and paediatrician; a Hospital University Assistant at the Child Neurology Department of Hedi Chaker Sfax University Hospital and member of "Neuropédiatrie" research laboratory (LR19ES15), University of Sfax. Email: jal.olfa90@gmail.com.

Sihem Ben Nsir is a Tunisian neurologist and paediatrician at the Child Neurology Department of Hedi Chaker Sfax University Hospital and member of "Neuropédiatrie" research laboratory (LR19ES15), University of Sfax. Email: sihembennsir@gmail.com.

Wafa Bouchaala is a Tunisian neurologist and paediatrician; a Hospital University Assistant at the Child Neurology Department of Hedi Chaker Sfax University Hospital and member of "Neuropédiatrie" research laboratory (LR19ES15), University of Sfax. Email: Wafabouchaala85@gmail.com.

Matilde Leonardi is an Italian neurologist and paediatrician. At present she is Director of Neurology in the Public Health, Disability Unit and Coma Research Centre at the Carlo Besta Neurological Institute in Milan.She is a FEAN, (Fellow of the European Academy of Neurology) and a WHO expert and consultant on neurology, disability, ageing and policy development. Email: Matilde.leonardi@istituto-besta.it.



Chahnez Charfi Triki is a Tunisian neurologist and paediatrician. At present she is a Professor of Neurology and the Head of Child Neurology Department Hedi Chaker Sfax University Hospital. She is a member of "Neuropédiatrie" research laboratory (LR19ES15), University of Sfax, Tunisia. Areas of interest: epilepsy in children, neurodevelopmental disorders including cerebral palsy and intellectual disability. Membership in ILAE-EMR; ICNA and the EPNS. Email: chahnezct@gmail.com.