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Caring for a child with type 1 diabetes during COVID-19 lockdown in a developing country: Challenges and parents' perspectives on the use of telemedicine

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ABSTRACT

Background and Aim: Jordan implemented abrupt and extreme lockdown measures to prevent the spread of COVID-19. This study aims to evaluate the effect of these measures on paediatric patients with type 1 diabetes in terms of acute metabolic complications and shortages in insulin and glucose measuring supplies. It also evaluates the caregivers' perceptions of the use of telemedicine during the lockdown.

Methods: This is a questionnaire-based cross-sectional study. It was completed using Google forms and patients/caregivers were asked to consent if they agreed to answer.

Results: 235 patients/families participated in the study. The mean age of the patients was 10.8 years ± 3.9 years (N = 229). Twenty-four children (10.2%) needed to visit the emergency department during the lockdown period which lasted for 10 weeks. Of these, eight (3.4%) were hospitalized due to acute metabolic complications. Families (58.3%) faced insulin shortages and 14% had to ration insulin, i.e., decrease the dose, during the lockdown. Glucose monitoring strips were rationed by 43.4% of families leading to more frequent low/high glucose readings in 75.5% of children of these families. Telemedicine using phones and social media applications was utilized for communication with healthcare professionals and continuing medical care. Most of the participants (85.5%) described it as a smooth and positive experience.

Conclusions: The extreme lockdown due to COVID-19 pandemic caused insulin and glucose measuring equipment shortages in children with diabetes in Jordan. However, the use of telemedicine for providing guidance and support was perceived positively by the families.

1. Introduction

Since the beginning of the year 2020, a very serious worldwide public health problem appeared due to the rapid spread of the novel corona virus disease (COVID-19).

Initial reports highlighted diabetes as a risk factor for a more severe course of the disease [1,2]. Children on the other hand, have seem to have a milder clinical course when infected with COVID-19 than adults. In addition, there are anecdotal, however, reassuring reports that children with dia-

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betes have not shown a different disease pattern compared to children who do not have diabetes [3].

The number of cases of COVID-19 in Jordan started to rise since March 15, 2020 after an outbreak during a wedding in the north of Jordan [4]. To control this imminent threat, the Jordanian government enforced extreme public health infection prevention and control measures. As of March 17, 2020, regulations were put in place to mandate social distancing, and all forms of internal and international travel were suspended. National curfew was ordered and administrative governorates were isolated from each other [5]. All hospitals were instructed to receive acute cases only. People were banned from using their vehicles and public transportation was stopped. In case of an emergency, people were instructed to call the national emergency services and an ambulance will be dispatched to the caller. This has resulted in a great pressure on these services. All forms of outpatient medical services were halted, as well as elective surgeries and non-urgent hospitalizations. Emergency departments recorded a very significant drop in the number of patients seeking help.

As Jordan has limited resources and is considered a middle income country [6], healthcare professionals face many challenges in providing comprehensive care for patients with type 1 diabetes (T1D). For example, the majority of paediatric patients, who present at diagnosis of T1D to the public hospitals in Jordan, are started on premixed insulin and reimbursement for self-monitoring of blood glucose is very limited [7]. The paediatric endocrinology clinic at Jordan University Hospital (JUH) was established in 2012 under the care of two full time paediatric endocrinologists where almost all T1D patients are started or switched to the basal-bolus regimen with self- monitoring of blood glucose. The level of care that is provided currently is considered an intermediate level where a comprehensive education is provided at the beginning of diagnosis and/or presentation to the paediatric endocrine clinic, followed by a three-month scheduled visit [8]. The patients are given a 30-day prescription that is renewed for three months until the next visit. In between visits, patients' enquiries are answered by contacting the health care professionals by phone or more commonly short message services and WhatsApp application. This is done by using phone numbers provided by JUH to the paediatric endocrinologists and the nutritionist that are shared with the patients/caregivers. These numbers are not dedicated solely to communicate with patients with T1D but are largely used for that purpose. Around 5 percent of our patients use flash glucose monitoring but less than one percent are using insulin pumps as all kinds of technology are not reimbursed by our public health insurance.

During the lockdown, a platform was initiated on the JUH website for the patients to register for medication renewals and healthcare volunteers would deliver the medications to patients houses. Two WhatsApp groups were created to announce these measures and to help with technical issues. We continued to manage our paediatric patients using WhatsApp and phone calls on individual basis throughout the curfew phase. After ten weeks, the lockdown was eased down, and the curfew continues till the writing of this document between midnight and six am each day.

This study aims to evaluate how the strict curfew affected our patients with T1D in terms of acute metabolic complications and whether they faced shortages in insulin supply or glucose measuring equipment that could have caused these complications. The study also describes the perception of patients/caregivers towards the use of telemedicine and social media as tools to reaching out to the patients and guiding them during the lockdown period.

2. Methods

2.1. *Study design*

This is a questionnaire-based cross-sectional study. Our target sample was patients with T1D, aged 1–21 years old, who attend the outpatient clinic at JUH. Three hundred and forty phone numbers of these patients/ caregivers were identified. They were contacted and asked to fill up a questionnaire that was sent to the two WhatsApp groups that were created during the lockdown period that lasted from March 17 till May 24, 2020.

2.2. *The questionnaire*

The questionnaire was designed to evaluate the effect of extreme lockdown on blood glucose control and acute metabolic complications in our patients with T1D. It also evaluates the accessibility and perception of telemedicine use among the participants during the lockdown. It was web-based and filled out using Google forms. Patients/caregivers could start answering the questionnaire only after consenting to do so. The consent paragraph states that this questionnaire is part of a study that is evaluating the impact of COVID-19 lockdown on the care of children with T1D, that the participation of the patients/caregivers is optional and that the information they provide is only used for study purposes. In addition, we clearly stated that if they choose not to participate, this will have no effect on the ongoing provided care for the child. Also, the patients/caregivers had the freedom to answer the questionnaire anonymously. During the lockdown, telemedicine was used for posting general information regarding COVID-19 and updates on any emerging reports from the world on the status of paediatric patients with T1D who were affected with COVID-19. It was also used to announce the measures that were taken to provide insulin supply during the lockdown. Finally, it was used for the continuing care of patients with T1D by answering any medical questions using phone calls, messages or WhatsApp. This was possible by sharing glucose readings from logbooks or the ambulatory glucose profiles for the ones who use flash glucose monitoring. Telemedicine was not used to carry planned appointments as the infrastructure for such service was not available. The questionnaire was written in Arabic and covered four major categories. Firstly, general information including age, sex, duration of T1D, last HbA1c before the lockdown and type of insurance. Secondly, questions related to the accessibility to general information on COVID-19 and diabetes, the source of the information the patients/caregivers got, how reachable was the medical team and how

the patients/caregivers perceived the process of telemedicine use during the lockdown. Thirdly, if the patient suffered from a COVID-19 infection or had any acute complication [severe hypoglycemia, persistent hyperglycemia or diabetic ketoacidosis (DKA)] that required emergency department visit and/or hospital admission during the lockdown. Finally, whether the patient faced shortages in insulin and glucose measuring supplies and possible consequences of that shortage.

2.3. Data collection and statistical analysis

The study design and its questionnaire were approved by the institutional review board (IRB) committee at the University of Jordan. Data was collected in the period between May 24 and May 28, 2020. Continuous variables were presented as mean ± SD and categorical variables were presented as frequency (%). Statistical analysis was conducted using SPSS® software (IBM, USA) version 25. Pearson correlation was used to examine association between the continuous variables. Independent-samples *t* test was used to find significant differences in the continuous variable between two groups. P values less than 0.05 was considered statistically significant.

3. Results

A total of 340 parents were contacted to complete the form. 237 families responded, of which, two declined to participate. The mean age of the patients (N = 229) was 10.8 years ± 3.9 y ears, and the mean value of HbA1c test before the lockdown was 8.3 ± 1.6% [(67.2 ± 17.0 mmol/mol) (N = 233)]. General characteristics of the participants are shown in Table 1.

3.1. HbA1c measurement during and after the lockdown

Most of the children did not have their HbA1c measured during the lockdown [214, (91.1%)]. The most common reason was fear from exposure to the Corona virus, 79 (36.9%), followed by the inability of hospitals that the child usually attends for medical care to receive patients, 70 (32.7%). The least common reasons were that the parents could not reach the hospitals during the lockdown due to the curfew and that the HbA1c test was not due, 64 (29.9%) for both. Participants could choose more than one option.

During the months of June and July, the lockdown was eased, and the out-patient services resumed gradually. HbA1c was measured in ninety-seven patients who participated in the survey and it was found that the HbA1c before the lockdown [8.3 ± 1.6% (67.2 ± 17.0 mmol/mol)] was significantly, but moderately correlated with that measured after the lockdown [7.8 ± 1.4% (61.7 ± 15.3 mmol/mol), Pearson correlation = 0.388, P value < 0.001.

3.2. Use of media and social media for COVID-19 awareness

Receiving information in this pandemic that relates to the critical medical condition of patients with diabetes is of great importance. More than one third of parents [88 (37.8%), N = 233] received information on how to deal with the COVID-19 crisis. More than half of these parents [51 (60.0%)] received information concerning COVID-19 and diabetes from the child´s treating physician via Facebook or WhatsApp, and a slightly higher percentage [54 (63.5%)] acquired information through personal search using different resources such as the media, social media, and internet. Participants could choose more than one option.

3.3. Parental attitudes and concerns

None of our patients with T1D was diagnosed with the COVID-19. Almost all parents [220 (93.6%)] felt the need to strictly abide to the safety measures and social distancing during the crisis because they were caring for a child with diabetes. Despite the cautious attitude, most parents [178 (75.7%)] were worried and felt insecure regarding the medical condition of their children. Sources of concern included fear of reduced immunity of children with diabetes, fear of shortages in insulin and glucose monitoring supplies, fluctuations in glucose levels, non-compliance of the child, expired insurances and increased consumption of food during the lockdown. A smaller percentage of parents [57 (24.3%)] were not worried due to several reasons; the blood glucose levels of their children were stable, safety measures and instructions for social distancing were strictly followed, easy accessibility to the treating physician and reassuring social media awareness posts created by the health care team.

Table 1 – General characteristics of participants.

Duration of diabetes N = 235	Percentage (%)	Metabolic control before lockdown N = 233	Percentage (%)
less than one year	25 (10.6%)	HbA1c $\leq$ 7.5% (58 mmol/mol)	84 (36.1%)
one year	29 (12.3%)	HbA1c > 7.5% (58 mmol/mol)	149 (63.9%)
2 years	33 (14.0%)	**Gender, N = 235**	
3 years	37 (15.7%)	Male	116 (49.4%)
4 years	34 (14.5%)	Female	119 (50.6%)
$\geq$5 years	77 (32.8%)	**HbA1c tested during lockdown, N = 235**	
Type of insurance, N = 235		Yes	21 (8.9%)
Governmental	187 (79.6%)	No	214 (91.1%)
Private	15 (6.4%)		
No insurance	33 (14.0%)		

3.4. *Telemedicine use during the COVID-19 lockdown*

Communication with the medical team through this long period of lockdown (ten weeks) was necessary. A significant number of parents [93 (39.6%)] needed to contact a member of the medical team. Most of the parents [201 (85.5%)] described the accessibility to members of the medical team through phone calls and/or WhatsApp as smooth.

3.5. *Acute metabolic complications during the COVID-19 lockdown*

Twenty-four children (10.2%) needed to visit the emergency department during the lockdown. Furthermore, eight children (3.4%) were hospitalized, for reasons mentioned in Table 2. Four participants out of the eight who needed to admit their children to hospitals believed that their arrival to the hospital was delayed by the curfew and fear of exposure to the corona virus.

At the same time period in 2019, twenty patients with T1D were admitted to JUH. Eleven patients were admitted electively for optimizing blood glucose control and education. The indications for the other nine admissions were: two newly diagnosed patients presenting with DKA, another two newly diagnosed patients without DKA, three previously known patients presenting with intercurrent illnesses without DKA and two previously known patients presenting with DKA due to incompliance issues.

3.6. *Insulin and glucose monitoring equipment shortages during the lockdown*

The COVID-19 extreme lockdown exerted tremendous challenges for the delivery and availability of medications to patients. This was reflected on the consumption patterns of insulin and glucose monitoring equipment Table 3.

Insulin rationing had no effect on the HbA1c values after the lockdown was over; children of families that reported the need to ration insulin doses did not have significantly higher values of HbA1c than those who did not [8.0 ± 1.6% (63.9 ± 17.5 mmol/mol), 7.8 ± 1.3% (61.7 ± 14.2 mmol/mol), respectively. P = 0.6]. In addition, children who were subjected to rationing of glucose test strips had similar HbA1c levels to those who did not ration the use of their glucose test strips, [7.6 ± 1.5% (59.6 ± 16.4 mmol/mol), 8.0 ± 1.3% (63.9 ± 14.2 m mol/mol), respectively. P = 0.212].

4. Discussion

The extreme lockdown measures that were imposed in Jordan explain the low rate of infections in the country. Fortunately, we suffer from cluster transmission rather than community transmission with 746 confirmed cases as of June 2, 2020 for a population of around 10 million people [9]. This might explain why none of our patients with T1D tested positive for COVID-19 till now. However, as these measures were so extreme and there was no time to prepare the healthcare system for this acute halt of continuous medical care, there was a great concern on how this would affect our patients whether already known to have T1D or presenting for the first time. More than 90% of our families did not attempt to do a follow up HbA1C during the lockdown due to fear of corona virus exposure, curfew, or halt of non-emergency services in the hospitals.

4.1. *Acute metabolic complications*

Non- compliance to insulin therapy was the major cause of DKA in the four previously known patients who were admitted during the lockdown. The only patient with new onset T1D had hyperglycaemia without DKA. The number of admissions to JUH for acute reasons during the lockdown was comparable to the number admitted at the same time period from last year (eight and nine respectively). The obvious difference is that there were no planned or non-emergent admissions during the lockdown as compared to eleven such admissions during the same period last year. The World Health Organization published a rapid assessment of service delivery for non-

Table 2 – Emergency department visits and hospitalizations of children with T1D during the COVID-19 lockdown.

Children who needed admission to the emergency department, N = 235	24 (10.2%)
Reasons for the emergency department visit, N = 235	
DKA*	4 (1.7%)
Hyperglycemia without DKA	8 (3.4%)
Hypoglycemia	4 (1.7%)
Insulin shortage	6 (2.6%)
Trauma	2 (0.9%)
Children admitted to the hospital during the lockdown, N = 232	8 (3.4%)
Causes of hospitalization	
DKA	4 (1.7%)
Hyperglycemia without DKA	2 (0.9%)
Hypoglycemia	1 (0.4%)
Urinary tract infection	1 (0.4%)
Direct Causes of DKA mentioned by the families	
Non- adherence to insulin therapy	4 (1.7%)
Curfew	0
Infection	0

* DKA: Diabetic keto-acidosis.

Table 3 – Shortages in insulin and glucose test strips supply during the COVID-19 lockdown.

Insulin shortages	Percentage (%)
Families that suffered from insulin shortages, N = 235	137 (58.3%)
Reasons for experiencing insulin shortages, N = 137 (participants could choose more than one option)	
• Inability to reach hospitals because of the curfew and lockdown	78 (56.9%)
• Medical institution that provided the insulin did not receive patients during lockdown	58 (42.3%)
• Insulin is expensive to buy	56 (40.9%)
• Fear from exposure to Coronavirus	48 (35.0%)
Families that bought insulin out of pocket during lockdown, N = 235	150 (63.8%)
Families that rationed insulin, N = 235	33 (14.0%)
Children who experienced hyperglycemia after insulin rationing, N = 33	18 (54.5%)
Did the family need insulin to be delivered during the lockdown? N = 235	
No	80 (34.0%)
Yes	155 (66.0%)
Was insulin delivered by the medical institution to families that needed insulin? N = 155	
No	53 (34.2%)
Yes	102 (65.8%)
Glucose test strips shortages	
Families that needed to buy glucose strips more than the usual during the lockdown, N = 235	175 (74.5%)
Families that rationed the use of glucose test strips, N = 235	102 (43.4%)
Children who experienced more frequent low or high blood glucose readings after rationing glucose test strips, N = 102	77 (75.5%)

communicable diseases during the pandemic which showed that during cluster transmission phase and community spread phase, diabetes services were disrupted in 50 and 62% of countries respectively [10]. In Italy, a drastic decline in emergency department visits was reported during the peak of the pandemic [11]. Moreover, a delay and more severe presentation of DKA during COVID-19 pandemic was reported from different regions of the world either due to delay, misdiagnosis of diabetes symptoms or difficulty in reaching healthcare facilities [12]. In our cohort four patients reported such difficulties.

4.2. *Use of social media applications and telemedicine*

In our situation, Telehealth was used as a tool to reach out for the patients to inform them on how to get their insulin supply delivered. This was helpful as around 100 families (65% of families who needed insulin to be delivered) reported that insulin was delivered to their homes when they filled the forms on the hospital's web site. In addition, some awareness posts on social media Apps regarding how to behave during the COVID-19 crisis reached around 38% of the families. More importantly, the easy accessibility to the medical team through telemedicine and the ongoing management using even simple tools such as logbook readings shared through social media applications (WhatsApp) enabled timely medical advice and prevented further acute metabolic complications that otherwise could have occurred. This was very clear as around 85% of families described the access to health care professionals as positive and smooth. Many colleagues have reported how this pandemic changed their practices and made the use of telemedicine a necessity and an efficient tool in managing patients with T1D virtually [13–18]. Even though these reports describe how telemedicine was significantly helpful in the context of the use of insulin pumps and glucose monitoring devices, we emphasize on its benefits even in a more basic way of T1D management through sharing images of logbooks and adjusting insulin regimens. Not surprising is the fact that the five percent of our patients, that use flash glucose monitoring, were also easy to follow by sharing their data virtually.

4.3. *Insulin and glucose monitoring rationing during the lockdown*

Most of our patients (86%) depend on insurance for their insulin supply. During the lockdown, more than half of the families faced insulin shortages despite the efforts in delivering insulin to the patients' houses. In addition, almost two thirds of the families had to buy insulin out of pocket, and this has led 14% of the families to start rationing insulin doses. Insulin rationing in patients with T1D is very dangerous as it leads to both acute and chronic complications [19,20]. In USA, it has been shown that one in four adults with T1D and families of adolescents with T1D reduce insulin doses due to cost issues [20–22]. Insulin rationing was also reported in a survey from different countries with various incomes. This survey has shown that patients with T1D from countries with lower income rationed insulin more than countries that have high income and comprehensive diabetes management programs [23].In addition, a higher percentage of families (43%), had to ration the use of glucose test strips which led to more frequent hypo/hyperglycaemic excursions in glucose levels in most of their children. This was not reflected on the HbA1c that was measured after the lockdown in these patients. This might be due to the small sample size, the fact that HbA1c does not assess glucose variability and whether the duration of the dysglycaemia was enough to affect the HbA1c levels. The higher percentage of glucose test strips rationing as compared to insulin rationing is logical as insulin availability is more important, and glucose monitoring is more expensive [24,25].

5. Conclusion

The extreme lockdown due to COVID-19 pandemic caused insulin and glucose measuring equipment shortages in children with T1D in Jordan leading to more out of pocket buying and increase in rationing of insulin and glucose monitoring. In addition, acute metabolic complications were mainly due to non-adherence rather than lockdown related reasons. Moreover, the patients'/caregivers' perception of the use of telemedicine during the lockdown was very positive. This points to the possible role of telemedicine in reaching out for patients and families of children with T1D, providing guidance and support for them through this difficult time and continuing a remote but possible medical management of these patients. These findings are important to plan for future possible crises and to emphasize the benefits of use of telemedicine in the continuous care of patients with T1D in more relaxed settings.

A limitation to our study is the lack of comparison between the cohort of patients that responded to the questionnaire and the group that did not. This can be attributed to the difficulty in defining the non-responders due to the option that was given to the participants to answer the questionnaire anonymously. Another limitation is the inability to compare the daily glucose readings prior and during the lockdown to objectively determine the effect of insulin and /or glucose test strips rationing on glucose variability in these patients.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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