

Challenges of patients with intrathecal baclofen pump therapy during COVID-19 pandemic in Saudi Arabia

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Background: This study was carried out to analyze the effects of the coronavirus disease 2019 (COVID-19) pandemic on patients with intrathecal baclofen (ITB) therapy.

Methods: Patients who came for ITB refill during the COVID-19 pandemic between March 2020 and August 2020 were contacted, and a survey was conducted regarding challenges faced during the COVID-19 pandemic. Data obtained from the chart review included demographics, diagnoses, pump information, baclofen dose, and COVID triage. Information was collected regarding travel arrangements, appointments, and problems related to ITB therapy or travel. The survey included 12 multiple-choice questions related to travel, appointment scheduling, and difficulties faced during the travel restrictions.

Results: The study included 19 patients with ITB (mean age: 38.1 ± 14.4) from outside Riyadh city who came for ITB refill during the COVID-19 pandemic. The majority of the patients were males. Spinal cord injury with paraplegia was the most common diagnosis (52.6%). In total, 7 patients had either clinical (31.6%) or travel-related difficulties (15.8%). No patient had ITB withdrawal at the time of the clinic visit. Nearly half (47.4%) of the patients had to change their appointment for refill. The percentage of patients who used a car as a mode of travel pre-COVID was 42.1%, which increased to 78.9% during the pandemic. They traveled 747.4 ± 356.6 km (7.4 ± 3.7 h) to reach the hospital for refill. Patients needed 1–4 accompanied persons for assistance during travel, with the majority (68.4%) requiring 2 accompanied persons. Statistical analysis did not reveal any significant associations between clinical or travel difficulties and appointment changes.

Conclusions: A pandemic or similar disaster can pose challenges to patients on ITB therapy living in areas with limited access to specialized care. In this study, none of the patients had serious complications or adverse outcomes; however, the main difficulties were attributed to travel. It is crucial to establish strategies at institutional, regional, or national levels to formulate guidelines for managing patients with ITB therapy during a pandemic.

Keywords: COVID-19, spasticity, Saudi Arabia, intrathecal baclofen, disability

Introduction

The coronavirus disease 2019 (COVID-19) pandemic imposed significant changes on health care systems around the world. Not only health care facilities were burdened with pandemic care, but also there were various challenges in providing routine care to persons with disability (PWD). Patients with intrathecal baclofen pumps (ITB) pumps are PWD who require special considerations for their baclofen pump management. Any interruption, delay, or dysfunction of baclofen pump can result in baclofen withdrawal or overdose, which could have serious implications. Due to

lockdown, travel restrictions, and limited access to care, timely refill of baclofen or access to emergency care was difficult during the COVID-19 pandemic.

In response to COVID-19, there were actions taken by the relevant authorities in Saudi Arabia to deal with the pandemic. Governance system and response strategies were set in place. The first case of COVID-19 was reported on March 2, 2020, while as of August 23, 2020, the Kingdom recorded 307,479 confirmed cases with a mortality rate of 1%^[1]. With the increase in number of COVID cases, primary health care centers, hospitals, and

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quarantine facilities were engaged to manage suspected and confirmed cases of COVID-19^[2]. Lockdown was strategically introduced, eventually leading to suspension of domestic and international travel^[1]. New admissions to inpatient rehabilitation facilities were generally on hold and beds were utilized to meet the demand of pandemic situation^[3]. KSA experienced two prominent peaks in the COVID-19 pandemic and recorded 841, 469 COVID-19 cases until May 6, 2023. The first peak lasted till December 2020, while the second peak started in December 2021^[4]. After the first COVID-19 case was reported, precautionary measures were implemented, including suspension of air and road travel. Public, social, and recreational activities were also restricted. This was followed by restrictions on commuting to work and implementation of total curfew in many cities^[1,4,5].

Not only PWD requiring admission were affected, but also challenges emerged in providing outpatient rehabilitation services. Though telerehabilitation was utilized as an alternate, certain PWD required in-person visit. This included patients with ITB pump who required pump refill. Failure to comply with ITB treatment or timely ITB refill can result in serious withdrawal, which can result in seizures, coma, or death^[6-8]. At any time, patients may endure an unexpected complication with the device system rendering the need of emergency care. Due to lockdown, it was important to ensure timely management and refill of ITB pumps. This was of utmost importance for patients coming from outside Riyadh city during intercity travel restrictions. Flights were limited, and road travel required special permits. The evolving situation required strategic improvisations with time. Attempts were made to carry out special arrangements for patients with ITB at clinical, administrative, and institutional levels.

This study was carried out to analyze the effects of COVID-19 pandemic on patients with ITB residing outside Riyadh City, and to highlight the associated challenges and complications.

Methods

Study type: Cross-sectional study.

Setting: Ambulatory setting, Rehabilitation Hospital King Fahad Medical City (KFMC), Riyadh.

ITB services at KFMC are provided by a multidisciplinary team, including rehabilitation physicians, neurosurgeons, rehabilitation nursing, and therapists as core team members. Ambulatory management of patients with ITB, including refills, is carried out at the weekly ITB clinic. During COVID-19 pandemic, the Rehabilitation Hospital at KFMC was converted to inpatient COVID-19 facility. Alternate arrangements for ambulatory services were made for patients with ITB based on the institutional formalities regarding COVID-19 screening and protocols. Patients were accommodated in emergency room or special allocated clinics based on hospital policy at the given time. Program coordinator served as the liaison person to arrange, track, and coordinate patients' visit during the pandemic. After restoration of routine services, patients resumed their routine follow ups at the weekly ITB clinic.

The study was approved by the Institutional Review Board. Patients from outside Riyadh City who came for ITB refill during COVID-19 pandemic between March 2020 and August 2020 were contacted, and a survey was conducted after obtaining informed consent. Patients were asked to fill in a survey with the

assistance of an investigator. Patients who were residents of Riyadh city were excluded. Data obtained from the chart review included demographics, diagnoses, pump information, baclofen dose, and COVID triage. Information was collected regarding travel arrangements, appointments, and problems in relation to traveling or ITB therapy. The survey included 12 multiple-choice questions related to travel, appointment scheduling and difficulties faced during the travel restrictions. Patients were asked if they experienced unusual clinical problems related to travel, including sleep problems, fatigue, increase in spasticity, bowel or bladder problems, missed medications, skin breakdown, fever, vomiting, seizures, or falls. They were also inquired about travel-related difficulties, including missed meals, difficulties at security checkpoints, vehicle-related problems, and lack of access to toilet for the disabled. The questionnaire was based on feedback from patients, empirical evidence, and clinical categories used in the literature^[9,10]. It was reviewed and finalized by physicians experienced in the management of ITB. After pilot testing on 4 patients, minor edits were made. Information regarding withdrawal, overdose, or loss of efficacy was obtained from the chart review as per the clinic assessment.

Statistical analysis

The Statistical Product & Service Solutions (IBM SPSS Statistics for Windows, Version 28.0) was used for data analysis. Normally distributed quantitative variables are expressed as mean \pm SD and categorical variables are presented as frequencies and percentages. The Fisher-Freeman-Halton exact test was applied to observe associations between categorical variables. The Mann-Whitney *U* test was applied to compare median hometown road distance with permit required to travel (yes, no). The Kruskal-Wallis *H* test was also applied to compare appointment change (postponed, preponed, and unchanged) with median hometown road distance. A *P*-value of <0.05 was considered statistically significant.

Results

The study included nineteen patients with ITB (mean age: 38.1 ± 14.4) from outside Riyadh city who came for ITB refill during the COVID-19 pandemic. The majority of the patients were males. The included patients had an average disease onset duration of 10.9 years with 7.2 years of standard deviation. These patients were on ITB for managing spasticity and dystonia. Spinal cord injury (SCI) with paraplegia (52.6%) was the most common diagnosis. Baclofen dose was changed (increased or decreased) for 5 patients (26.4%) at the time of clinic visit during pandemic study period. Also, drug volume in the pump (ie, 20 vs. 40 mL) during refill was changed for 3 patients. Drug volume for 2 of them was decreased from 40 to 20 mL, while 1 patient required an increase of drug volume from 20 to 40 mL. This was to adjust refill intervals in relation to their dosage. Nearly half of the patients required modifications in their appointments for refill (Table 1) mainly due to adjustments in travel arrangements during lockdown. Hence, their refill interval was different as compared with their routine before the pandemic. The time since the last ITB refill was between 49 and 221 days.

No patient had ITB withdrawal at the time of presentation to the clinic. In addition, patients were triaged for respiratory signs and symptoms as per COVID-19 protocols, and no patient

Table 1
Demographic characteristics and baclofen pump details at clinic visits during COVID-19 pandemic.

Characteristic	Description	N (%)
Age (y)	Mean ± SD	38.1 ± 14.4
Gender	Male	12 (63.2)
	Female	7 (36.8)
Home town distance from KFMC (km)	min-max (mean ± SD)	53-1138 (747.4 ± 356.6)
Diagnosis	Anoxic brain injury	1 (5.3)
	Cerebral palsy	1 (5.3)
	Spinal cord injury—paraplegia	10 (52.6)
	Spinal cord injury—tetraplegia	6 (31.6)
Duration since disease onset (y)	Traumatic brain injury	1 (5.3)
	Mean ± SD	10.9 ± 7.2
ITB placement	King Fahad Medical City	7 (36.8)
	Another Institute in KSA*	7 (36.8)
	Outside KSA*	5 (26.3)
Duration since first ITB placement (y)	Mean ± SD	5.92 ± 3.50
	Pump volume (mL)	20 (21.1)
Baclofen concentration (mcg/mL)	20	4 (78.9)
	40	15 (78.9)
	500	2
	1000	6
Baclofen dose (mcg/d)	1500	2
	2000	9
	Median	299.8 (160.1–443.5)
Low reservoir alarm volume (mL)	Median	2 (2–3)
Duration since last ITB refill (d)	Min-max (Mean ± SD)	49–221 (149 ± 49.9)
	Min-max (mean ± SD)	0–173 (24.3 ± 40.3)
Days remaining to low reservoir alarm date	Decreased	1 (5.3)
	Increased	4 (21.1)
	No change	14 (73.7)
Change in concentration	No	19 (100.0)
	Yes	3 (15.8)
Change in drug volume (i.e., change between 20 mL and 40 mL)	Decreased	1 (5.3)
	Increased	3 (15.8)
Change in low reservoir alarm volume	No change	15 (78.9)
	Since previous visit; min–max (mean ± SD)	66–355 (169.6 ± 72.5)
	Till future visit; min–max (mean ± SD)	66–281 (158.3 ± 49)
Change in refill interval (d)	Unchanged	9 (47.4)
	Increased; min–max (mean ± SD)	5–39 (23.5 ± 16.6)
	Decreased; min–max (mean ± SD)	6–186 (51.5 ± 67.6)
	Decreased	6 (31.6)

*Kingdom of Saudi Arabia

required further testing. None of the patients required hospitalization at the time of the clinic visit. Nearly half of the patients (47.4%) had to change their appointment for refill. Moreover, 5 patients (26.3%) were accommodated on other working days rather than Monday, which is our routine ITB clinic day.

Eight out of 19 patients (42.1%) were using their private car as a usual mode of traveling before the pandemic. During the

pandemic, 15 out of 19 patients (78.9%) used their private car for travel. The patients and their companions traveled 747.4 ± 356.6 km (7.4 ± 3.7 h) on average to reach our center. The approximate distance and travel duration by road from home town to KFMC based on Google map was between 53 km (1 h) and 1138 km (12 h) (Fig. 1). In addition, 2.7 ± 1.4 days on average are needed to complete a round trip for all the patients. Patients needed 1 to 4 accompanied persons either assistance, driving, or both. The majority of the patients (68.4%) needed 2 accompanied persons (Table 2).

Regarding difficulties faced during refill visits in lockdown, 6 patients (31.6%) reported clinical difficulties, while 3 patients (15.8%) had travel-related difficulties. The clinical difficulties included sleep problems, fatigue, increase in spasticity, bowel/bladder problems, and falls. Although travel-related difficulties included, stops at more than one security checkpoint, car malfunction, and lack of access to disabled toilets (Tables 2 and 3). In total, 7 patients had either clinical or travel difficulties, whereas 2 patients reported both clinical and travel difficulties during their traveling. Six of those 7 patients had SCI (4 tetraplegia, 2 paraplegia), and one had a diagnosis of anoxic brain injury.

Table 4 is the presentation of findings for the χ^2 association test. Various possible factors associated with appointment changes were analyzed. Results have shown no significant association between these factors and appointment changes. Only permit requirements for travel purposes were associated with appointment status; however, this association can be significant at a 5% level of significance if the sample size was large.

Results presented Table 4 showed median hometown distance in relation to appointment changes; however, the difference was not statistically significant $P = 0.737$. Kruskal Wallis H test was used to examine the difference in various categories of appointment changes. Similarly, the median hometown distance for patients who required a travel permit was 947 km (IQR: 861.3–1059.0), which was comparatively less for those who did not require travel permit and had a median distance of 637 km (IQR: 226.0–1055.0). The difference was not statistically significant ($P = 0.909$).

Discussion

The COVID-19 pandemic imposed immense pressure on health care systems worldwide, including health care system in KSA. This global crisis dramatically depleted hospital resources causing significant challenges in health care delivery^[5,11]. Due to concerns of morbidity and mortality associated with baclofen withdrawal in the setting of delayed refill or pump malfunction, patients with ITB require 24/7 access to specialized care. Any delays in refill or management of a pump malfunction may result in serious baclofen withdrawal. Clinical features of baclofen withdrawal range from mild symptoms, like spasticity exacerbation and pruritus, to more severe complications, like fatal multiorgan failure^[12–17]. COVID-19 pandemic posed significant challenges for PWD^[11]. Individuals with ITB in particular were at high risk of complications due to lockdown, city-wide curfews, travel restrictions, quarantine formalities, and overwhelming resource utilization for patients with COVID-19. These factors limited their timely access to their specialized health care needs. A very limited data was published in this regard globally^[9,10]. Given the unique attributes of health care systems in KSA and the Gulf

Table 2
Patients' experience regarding traveling and appointments and clinical difficulties for baclofen pump refill visits during the COVID-19 pandemic.

Characteristic	Description	N (%)
Permit required and obtained to travel	No	11 (57.9)
	Yes	8 (42.1)
Difficulty in obtaining permit	Yes	3 (15.8)
	No	5 (26.3)
	Not applicable	11 (57.9)
Permit valid for travel back on day of clinic visit	Yes	5 (26.3)
	No	3 (15.8)
	Not applicable	11 (57.9)
Total days of round trip	min - max	1-7
	Mean ± SD	2.7 ± 1.4
	Median	3 (2-3)
Medical report provided to travel prior to clinic visit	No	9 (47.4)
	Yes	10 (52.6)
Mode of travel for ITB refill appointments (during lockdown)	Car-private	15 (78.9)
	By air	4 (21.1)
Mode of Travel for ITB refill appointments (prior to lockdown)	Car-private	8 (42.1)
	By air	11 (57.9)
Travel duration car (for those who traveled by car)	min - max	1-12
	Mean ± SD	7.4 ± 3.7
	Median	8 (4-11)
Number of accompanied persons	One	3 (15.8)
	Two	13 (68.4)
	Three	2 (10.5)
	Four	1 (5.3)
Role of accompanied person (s)	Drive and assist	15 (78.9)
	Assist only	4 (21.1)
Assistance provided and appointments confirmed to patient/family by the clinic staff or coordinators.	No	3 (15.8)
	Yes	16 (84.2)
Notification visit provided to the patient for assistance in traveling back to avoid fine due to intercity lockdown.	No	7 (36.8)
	Yes	12 (63.2)
Patients facing clinical difficulties during traveling	Sleep problems	2 (10.5)
	Fatigue	1 (5.3)
	Increase in spasticity	2 (10.5)
	Bowel or bladder problems	1 (5.3)
	Falls	1 (5.3)
	Missed oral medications	0 (0.0)
	Skin breakdown	0 (0.0)
	Fever	0 (0.0)
	Vomiting	0 (0.0)
	Seizures	0 (0.0)
	Total	6 (31.6)

coordinator to go through screening process and finally reach the designated area for ITB refill.

The most common clinical symptoms associated with traveling during the pandemic in our study were sleep problems and an increase in spasticity. Overall, nearly one quarter (26.4%) of our study participants required ITB dose adjustment at their refill visit, with one patient requiring decrease in dose. Two out of 4 patients who reported increase in spasticity had a diagnosis of SCI

Table 3
Association of various factors with the change of appointment due to lockdown.

Factors	Was appointment changed due to lockdown situation?				P	
	Postponed, n (%)	Preponed, n (%)	Unchanged, n (%)	Total, n (%)		
Permit required to travel	No	1 (9.1)	2 (18.2)	8 (72.7)	11 (100)	0.080
	Yes	4 (50.0)	2 (25.0)	2 (25.0)	8 (100)	—
Any difficulties faced during traveling (clinical)	No	3 (23.1)	2 (15.4)	8 (61.5)	13 (100)	0.493
	Yes	2 (33.3)	2 (33.3)	2 (33.3)	6 (100)	—
	Sleep problems	No	4 (23.5)	3 (17.6)	10 (58.8)	17 (100)
	Yes	1 (50.0)	1 (50.0)	0	2 (100)	—
Fatigue	No	5 (27.8)	3 (16.7)	10 (55.6)	18 (100)	0.138
	Yes	0	1 (100)	0	1 (100)	—
Increase in spasticity	No	4 (23.5)	4 (23.5)	9 (52.9)	17 (100)	0.622
	Yes	1 (50.0)	0	1 (50.0)	2 (100)	—
Bowel or Bladder problems	No	5 (27.8)	3 (16.7)	10 (55.6)	18 (100)	0.138
	Yes	0	1 (100)	0	1 (100)	—
Missed oral medications	No	5 (26.3)	4 (21.1)	10 (52.6)	19 (100)	—
	Yes	0	0	0	0	—
Skin breakdown	No	5 (26.3)	4 (21.1)	10 (52.6)	19 (100)	—
	Yes	0	0	0	0	—
Fever	No	5 (26.3)	4 (21.1)	10 (52.6)	19 (100)	-
	Yes	0	0	0	0	—
Vomiting	No	5 (26.3)	4 (21.1)	10 (52.6)	19 (100)	—
	Yes	0	0	0	0	—
Seizure	No	5 (26.3)	4 (21.1)	10 (52.6)	19 (100)	—
	Yes	0	0	0	0	—
Falls	No	5 (27.8)	4 (22.2)	9 (50.0)	18 (100)	0.622
	Yes	0	0	1 (100)	1 (100)	—
Any difficulties faced during traveling (travel related)	No	3 (18.8)	3 (18.8)	10 (62.5)	16 (100)	0.114
	Yes	2 (66.7)	1 (33.3)	0	3 (100)	—

with tetraplegia, out of which one required dose adjustment at the time of refill. Increase in spasticity was also reported in another study on ITB management during the COVID-19 pandemic, in which D'Ercole et al^[10] reported that 35% of patients had worsening symptoms related to spasticity, and half of the patients requested an increase in daily dose of baclofen. Findings of sleep problems and increase in spasticity need to be interpreted with caution as patients generally do experience increase in spasticity with prolonged travel, and dose adjustments are routinely carried out at refill visits for patients who report change in spasticity at home. However, the most important findings in our study were that none of the patients had any serious complications or adverse outcomes due to the COVID-19 pandemic or lockdown situation, and no patient required admission. None of the participants had COVID-19 at the time of initial screening during refill visit, and

Table 4
Comparison of median hometown distance in relation to change in the appointment and travel permit.

	Categories	N	Median distance (km)	IQR	Min (km)	Max (km)	P
Appointment	Postponed	5	843.00	(714.0–1042.5)	714	1138	0.737*
	Preponed	4	931.50	(706.8–1028.0)	637	1055	—
	Unchanged	10	622.50	(192.0–1060.3)	53	1138	—
Permit	Not required	11	637.00	(226.0–1055.0)	53	1138	0.909†
	Required	8	947.00	(861.3–1059.0)	714	1138	—

*P-value based on Kruskal-Wallis H test.

†P-value based on Mann-Whitney U test.

no patient had baclofen withdrawal or pump malfunction. Further analysis showed that clinical difficulties were not significantly associated with travel adjustments.

Road and air transportation are KSA's primary modes of intercity travel^[19,20]. Factors like travel time, waiting time, cost, and comfort influence the choice of mode of travel for the Saudi population^[19]; however, traveling of PWD is impacted by the degree, duration, and type of disability^[21,22]. During the lockdown period, domestic air flights and public transportation were suspended, while traveling by car required a special permit^[1]. Our results found that the requirement of a permit for travel was significantly associated with the appointment changes due to the lockdown situation. Distance traveled by the patients in our study varied from 53 to 1138 km, with an average of 747.4 km. With the suspension of air travel, individuals from distant locations faced a particular burden as they had to rely on car transport for long commuting. Before the COVID-19 lockdown, less than half of the patients (42.1%) were using the car as a preferred means of travel, which increased to 78.9% during the lockdown period. It is important to note that Saudi Arabia is known to have sweltering and dry summers, where temperatures can go up to 46 °C^[23]. This placed additional physical and logistical burden on these patients, making access to care even more challenging in an overwhelming pandemic situation. To adapt to the challenges posed by travel restrictions and to minimize COVID-19 exposure, almost half (47.4%) of the appointments for baclofen refills were rescheduled, either by preponing or postponing them. Patients' appointments were adjusted based on pump reservoir volume, low reservoir volume alarm date, travel distance, and convenience to commute. Nearly one-quarter of the patients were accommodated on days other than Monday's routine ITB clinic day, requiring staff and logistic allocations accordingly. This was carried out in close coordination with the program coordinator. Before clinic visits, planning and effective communications are recommended to manage patients with spasticity and ITB therapy during pandemic^[9,10,24].

Generally, factors like social distancing, risk of COVID-19 infection, and safety were reported considerations for travel during the pandemic^[25]; however, for patients with ITB, additional factors had to be taken into consideration. Firstly, dependency on PWD, regardless of their pump status influences travel planning. On average, patients in our study traveled 747.4 ± 356.6 km (7.4 ± 3.7 h) to reach our center. In addition, 2.7 ± 1.4 days on average were needed to complete a round trip for all patients. Patients and their families had to make arrangements for overnight stay. They not only had to ensure COVID precautions but also had to consider disability friendly accommodation as well. Second, access to disability-friendly services during the journey was another consideration. Third, patients

with ITB need to ensure precautions specifically related to the baclofen pump, as pump functioning can change due to extremes of temperature, environmental pressure changes, or exposure to electromagnetic interference. This is in addition to the risks associated with delayed refill or pump malfunction. Fourth, cost of travel can be affected due to mode and frequency of travel for refills and number of persons accompanying the patient to provide assistance during travel. In our study, patients required 1–4 persons for assistance, with the majority (68.4%) of patients requiring 2 accompanying persons. These unusual travel circumstances integrated with patients' disability add more burden on families/caregivers. It has been reported that caregivers who commute for medical trips are vulnerable to issues related to travel and financial burden, in addition to the impact on work and family commitments^[26]. Furthermore, given that PWD may be vulnerable to COVID-19 infections, high-risk patients need to be identified prior to their travel and facilitated accordingly. For example, in our study, majority (84.2%) of patients had SCI, with nearly one-third of total participants having diagnosis of SCI with tetraplegia. Patients with tetraplegia are at risk of respiratory infections due to impaired ventilation. A routine pump refill visit during COVID-19 pandemic, either via air travel or a long-distant commute to a hospital (which is already operating as a COVID-19 center) required a high vigilance at all times.

Our study brings patient's perspectives into consideration. It is important to have feedback and keep patient experiences under considerations during a pandemic. While health care providers and stakeholders would consider their best judgment to ensure sustainable, efficient, and quality care during a disaster situation, they may not be able to capture the holistic view without taking the opinions of ones receiving that care. Our study was intended to highlight those challenges from a patient's perspective. The fear and worry of baclofen withdrawal due to the inability to reach the facility on time could be stressful, not only for the patient but also for the health care providers. Similarly, in a lockdown situation, lack of clarity on obtaining emergency care in case of pump dysfunction could be a daunting experience. Though our study was focused on clinical and nonclinical challenges, the emotional and psychological impact of lockdown on patients with ITB was not emphasized in our study. Future studies to highlight psychological factors can bring stronger emphasis in establishing holistic care for patients with ITB during a lockdown situation.

This study provides insight into different aspects of care related to patients on ITB therapy and highlights the specialized needs of this vulnerable population with disability in a pandemic situation. Delayed refill or pump malfunction during a disaster situation such as pandemic can pose health risks of critical nature. Our study emphasizes the strategies adapted to minimize the risks

involved in such situations. Challenges beyond the clinical nature, such as caregiver burden and travel-related difficulties, were also highlighted. Though the findings of these studies are more relevant to regional health systems, given the rarity of global literature published in this context, this study provides a wake-up call to ITB centers worldwide to develop coping strategies in disaster situations other than pandemics. This may range from man-made disasters to natural disasters such as earthquake, floods, nuclear accidents, or regional conflicts. In health systems, where local centers are not resourceful to provide specialized care in emergency situations, stringent selection criteria for ITB therapy should be set in the first place. One of the main criteria for having patients on ITB therapy is to ensure that they have access to specialized centers in case of emergency. Authorities at all levels of health care should ensure this criterion is clearly met. Among our participants, majority of the patients had their pump placement at centers other than our institute. They preferred to establish care at our center mainly due to financial issues limiting continuation of care at other hospitals, closure of ITB service at the primary institute or because their pumps were placed outside KSA and they wanted to establish care at a governmental hospital. Nonclinical stakeholders may not be aware of the seriousness of the problems with interrupted ITB therapy. This renders the need of urgent actions to be adapted as summarized below: (1) Institutional, regional, or national policies need to be set in place to ensure proper selection criteria for ITB therapy. (2) Clear guidelines for patients with ITB during a disaster situation should be ascertained. (3) Guidelines specific to subgroup of disaster type can be introduced. (4) Nonclinical stakeholders need to be engaged in policy-making, including supply chain, transport, emergency response teams, and governing authorities. (5) National registry of patients with ITB should be set in place. (6) For regional pockets without ITB expertise, local health care providers need to be trained to facilitate the care of the patients with ITB. (7) Standalone ITB emergency response team can be arranged at a regional or national level to manage disaster situations. (8) International collaborations with expertise can help to develop strategies pertaining to similar challenges. (9) Central process at federal or state level to ascertain readiness of ITB service at an institute may be considered before approval of starting ITB program. (10) Introduction of ITB accreditation program by health accreditation authorities can set standards across the world. (11) Telemedicine should be integrated across ITB programs formally. (12) All clinical and nonclinical stakeholders at an institutional service need to have formal training and competencies in managing patients with ITB. (13) Community resources, peer support groups, and nonprofit organizations can improve networking among patients and related stakeholders, especially to share experiences and provide support in situations of emergencies or disasters. (14) Research and publications by experts handling patients with ITB need to be encouraged to improve evidence-based care.

Limitations

One of the main limitations of the study is the small sample size, which prevents inferential statistics. Another limitation is that the survey information was collected retrospectively, which could be subject to recall bias. Though this study primarily focused on patients' challenges and difficulties, future studies can address the burden on accompanying family members or caregivers.

Furthermore, conducting a similar study with a more extensive and diverse Saudi population of PWD can provide deeper insights into the challenges faced by them during pandemic or disaster situations.

Conclusions

Patients with ITB need to be identified as a high-risk and vulnerable population in a disaster situation. A pandemic or similar disaster can pose challenges to patients on ITB therapy living in areas with limited access to specialized care. Our study concludes that none of the patients had serious complications or adverse outcomes; however, main reported difficulties during COVID-19 pandemic were travel related. Strategies need to be in place at institutional, regional, or national level to develop guidelines to deal with patients with ITB therapy during a pandemic. This would render the need of involving clinical and nonclinical stakeholders to ensure continuity of care of patients on ITB therapy.

CRedit author statement

A.Z.Q. contributed with design, manuscript preparation, editing and review, H.S. contributed with study design and manuscript review, M.J. contributed with data acquisition and manuscript preparation, W.S. contributed with statistical analysis and manuscript preparation, F.Q. contributed with manuscript editing and review, L.L.S.O. contributed with data acquisition, T.W. contributed with statistical analysis and manuscript preparation.

Declaration of competing interest

The authors declare that they have no competing interest.

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Ethics statement

The study was approved by the institutional review board, King Fahad Medical City, Riyadh (IRB No. IRB 20-415). All participants provided written informed consent.

Data availability statement

The data used to support the findings of this study are available from the corresponding author upon request.

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Declaration of generative AI and AI-assisted technologies in the writing process

No AI tools/services were used during the preparation of this work.

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