

Rehabilitation services for children with disabilities during the COVID-19 pandemic in the United Arab Emirates: Experiences of parents

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Introduction: The Covid -19 pandemic brought changes in professional practice across the globe. Children with disabilities received rehabilitation services remotely throughout the lockdown periods to contain the virus in the United Arab Emirates. This paper explores the experiences of parents of children with disabilities who received remote rehabilitation services during the Covid-19 pandemic.

Methods: A survey was developed by the study team in English and Arabic. Demographic data, characteristics of children, family circumstances, access to rehabilitation, use of assistive tools, financial and psychological implications on parents and children, and future use of remote therapy. It was deployed to the parents through the rehabilitation centers and was analyzed using descriptive statistics with frequencies and percentages.

Results: The survey was completed by 239 parents whose children with disabilities received the rehabilitation services remotely mainly through telerehabilitation. The pressure and psychological impact on parents were high, reporting frustration (44.8%), and anxiety (59.8%), although (70.3%) recognized the importance of continued care for the child.

Conclusion: Telerehabilitation was the means during the pandemic to ensure continued care in the UAE. In the future, remote rehabilitation will be appropriate in specific situations when there is limited or no access to the center. Future research should explore the continued use of telerehabilitation and its effectiveness.

Key words: COVID-19; TELEREHABILITATION; CHILDREN WITH DISABILITIES

INTRODUCTION

The COVID- 19 pandemic has seen changes in professional practice across the globe. Almost all sectors working with non-essential services were closed for the first few days to reduce the spread of infection including rehabilitation centers in the United Arab Emirates (UAE). But within a span of fortnight, it was encouraged health and rehabilitation centers to consider alternate ways of providing services for those requiring ongoing care. The importance of continued care for the disabled were crucial and one of the cost-effective ways to continue care in their own homes during the

Covid-19 pandemic that included synchronized video calls through telerehabilitation, pre-recorded therapeutic videos and online programs (1-4).

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Due to the restriction of movements imposed to contain the virus, residents were confined to their homes for over a year in the United Arab Emirates (UAE). This included even children with disabilities, who normally would receive a range of integrated services including special education and therapeutic interventions by multidisciplinary teams. Remote rehabilitation services, mainly through telerehabilitation, were offered in the UAE to the children with disabilities (1).

Prior to the pandemic, the use of telerehabilitation was highly limited for children with disabilities (5) although it was an accepted and feasible means of providing therapy (6, 7). It was reported to be comparable to usual care (8). There have been articles on the quick utilization of telerehabilitation during the COVID-19 pandemic (9-11) that changed practice experiences for all stakeholders within the rehabilitation settings. *Camden and Silva* (2021) suggest considering family-centeredness of the services offered remotely as the implementation of telerehabilitation was a quick response to COVID-19 situation. However, there were no published studies in the UAE on the provision of rehabilitation services and parents' experience during the lockdown of the COVID-19 pandemic when this study was undertaken.

The main aim of this study was to investigate the rehabilitation services provision by exploring the experiences of parents of children with disabilities during the COVID-19 pandemic. This paper explored the access to rehabilitation services, engagement of parents and children during the therapy and challenges faced by parents during the COVID-19 pandemic in 2020 with the following specific research questions.

1. How did the parents or carers organized themselves to manage the child with disability at home while managing other commitments (other children, their work) in the UAE during COVID-19?
2. What services and support were offered to the parents or carers from the rehabilitation centers?
3. What were the challenges faced for utilizing the rehabilitation services during the COVID-19 pandemic?
4. What were the psychological implications of receiving therapy since the pandemic?

METHODS

The study was conducted in the pandemic during the lockdown period in the UAE between January to April 2021. The intended participants for this study were the parents of children with disabilities receiving services from reha-

bilitation centers. The survey link for the study was sent to major rehabilitation centers, requesting them to forward it to the parents of the children receiving rehabilitation services, as the researchers did not have direct access to the parents. A period of four weeks was allotted for completing the survey, and a follow-up request was sent to the centers in the second week to encourage parents to participate in the study.

The researchers for the study were from the centers providing rehabilitation services for children with disabilities in collaboration with a higher education institution based in the Emirates of Abu Dhabi. Ethical approval for the study was granted from the higher education institution (No: INTSTF013PHY20). The survey was developed by the research team based on the concepts of remote therapy and considering the lockdown situation in the UAE during COVID-19 in the year 2020.

The survey questions were in both English and Arabic and were validated using two-step processes. Firstly, the face and content validity were done by two experts in the field and the pilot was sent to eight parents from one rehabilitation center in Abu Dhabi. Minor modifications were made following the validation process that increased the clarity of questions.

In order to meet the aims of this research, the questionnaire was developed with five different sections with the likely responses. The responses were added with a wider variety of choices with multiple response questions or with dichotomous response of 'yes or no' rather than open-ended questions. The details of the five sections are outlined below:

1. The first domain was on family circumstances that explored the number of children, work, ability in managing between disabled and other children, responsible person for providing rehabilitation at home for the child, main obstacles, and access to rehabilitation.
2. The second domain explored in detail the rehabilitation services offered, the child's co-operation and engagement to therapy at home.
3. The third domain included questions regarding access and use of assistive devices such as what assistive tools were available for the child, accessibility to the equipment or devices for therapy and maintenance services offered or available during the pandemic.
4. The fourth domain explored the psychological implications that the child and the parents had during the lockdown. The questions were related to differences in relationships between siblings and disabled child, negative and positive impact on the child and parent.

5. The fifth and the final section was to seek the parents' suggestions on the remote rehabilitation if continues for longer during the pandemic or had to be adopted in the future post pandemic

The survey was analyzed using descriptive statistics. Frequency and percentages were used to present the data.

RESULTS

Demographic data and family circumstances

The survey was filled by a total of 239 parents of children with disabilities. The responses to this survey were received from the six emirates of the UAE. The most responses were from the Emirate of Abu Dhabi (84.4%), Dubai (9.8%), Sharjah (2.7%), Ajman (1.8%), Fujairah (0.9%) and Ras Al Khaima (0.4%).

Male respondents were slightly higher (56.1%) than females (43.9%) as the surveys were filled either the mother or father of the child. Mother being the main carer of the child at home (78.7%), followed by father (9.2%) and other family members or nanny (12.1%).

The average number of children within these families was reported to be four, and about 75.3% respondents have one disabled child in their family. Approximately 66% of the respondents reported having difficulty managing the children with disabilities at home during the COVID -19 pandemic. This was mainly due to other commitments at home with other children (28.9%) and lack of support from other family members (23%) and work commitments (28.9%).

The type of disabilities that the children had were diverse including cognitive, physical, behavioral, sensory impairments and multiple disabilities, with largest number of children on the autism spectrum as shown in Fig. 1

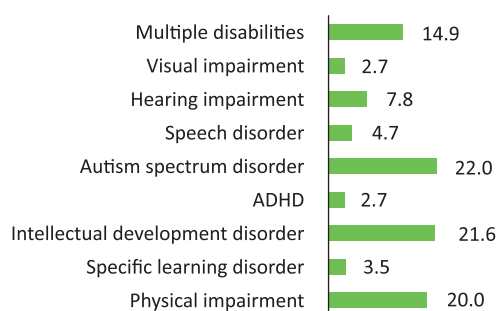


FIGURE 1. Type of disabilities.

The parents reported that the child spent most of the time at home on the phone or tablet (65.1%), playing with siblings (43.5%), some helped parents in household chores (18.8%), doing craft work (16.5%) and some children not being active (25.95).

Rehabilitation Services during COVID-19 pandemic

The services received during the lockdown were Physiotherapy (44.8%), Occupational Therapy (49.4%), Speech therapy (45.4%), Special Education (34.6%), Social Counseling (14.2%), Psychological (10.2%), Hearing Solutions (4%).

The types of rehabilitation services received during the pandemic were either home visits (30%) or tele rehabilitation (70%). The frequency of therapy was similar to pre-pandemic (47%), less than the pre-pandemic (49%) and more than pre-pandemic (4%).

In accessing telerehabilitation, the participants reported several enablers and barriers. One of the largest enablers was that therapists were setting appointments well in advance for the parents to organize themselves (22.6%). Other enablers are provided in Table 2. There were a number of barriers being reported as the parents were busy managing home and other children (51.9%) and also was the financial issues (35.1). The other barriers are listed in Table 2.

6.15% of parents expressed that it was challenging to provide therapy at home and one of them was child being child's non-cooperation (13.8%) and poor co-operation (19.8%). Despite these challenges, 68.2% reported to cope well with children during the therapies at home.

The parents felt that the child did not pay enough attention during telerehabilitation (56%), or that it was rejected by the child (36%), lacked fun and engaging activities (25%), and caused tiredness due to multiple sessions (5%). 30.6% of parents reported weight gain of the child during the lockdown.

The parents reported changes in certain aspects of child's function and reported improved communication (20%), improved daily activities, especially dressing and eating (20.8%), better social interaction (13.3%), grasping and holding (11.4%) and walking (10.6%).

Access and use of assistive devices

52% of the parents reported having access to assistive devices to carry on with the therapy at home. Assistive devices used at home were communication aids (37.6%), daily living aids (33.3%), mobility aids (27.1%), & visual aids (11.4%). The access to maintenance services of assistive devices during the lockdown was reported by 24.7%.

Psychological changes and impact during the lockdown

Most parents (82%) reported changes in behavior in the child during the lockdown. Most of the parents felt that their child would have been happier receiving therapy at the center (57.6%) when compared to telerehabilitation

TABLE 1. Demographic details and family circumstances (N=239).

Characteristics	Attribute	Frequency, %
Gender of respondents	Male	56.1
	Females	43.9
Main carer of the child with disability at home	Mother	78.7
	Others	22.3
Gender of children with disabilities	Male	61.6
	Females	38.4
Ages of children, (years)	0-4	11.8
	5-9	27.8
	10-14	28.2
	15-18	14.5
	18+	17.5
Number of children with disabilities in the family	One child	75.7
	Two	8.4
	More than two	15.9
Employment status of parents	Not working since covid	10.5
	Full time employment	62.0
	Part time employment	18.3
	Never worked	9.2
*Leisure activities	Use of electronic devices	65.1
	Playing with siblings	43.5
	Helping parents	18.8
	Craft work	16.5
	No activity	25.9
Negative behavior of the disabled child during the lockdown	Aggression	25.9%
	Lack of motivation to work or study	36.4%
	Complaining of tiredness	15.1%
Reported improved relationship between disabled child with the other siblings. The siblings were	More empathetic	38.1
	Supportive	34.3
	Caring	36
	Increased sharing while playing	33.5
	Acceptance	23.4
Comparison of child status between pre-pandemic and during pandemic	No difference	42.7
	Deterioration	27.8
	Improvement	25.1

*more than 100% due to multiple options

TABLE 2. Enablers and barriers to telerehabilitation (N=239).

* Enablers	Frequency, %
Clear and timely appointments	22.6
Safe environment at home	14.6
Flexible hours	14.6
Training parents on the technical aspects of telerehabilitation	13
Provided lecture materials and resources on therapies	9.2
Provided electronic such as laptop or tablet to run telerehabilitation at home	2.9
* Barriers	
Busy with other children and tasks at home	51.9
Financial issues	35.1
Fear of applying therapy at home	23.8
Lack of informational services	23.8
Lack of tools and equipment	21.8
Internet or device problems	19.2
Other technical issues	11.3

*more than 100% due to multiple options

(11.8%), children showed aggression (25.9%), were in low mood (26.4%), lacked motivation to work or study (36.4%), consumed more time than usual (16.3%), lack of social interaction (41.8%), complained of tiredness (15.1%), lack of sleep (20.9%) and feeling anxious (25.1%).

The parents also reported improved relationships between siblings during the lockdown period (70%). Siblings became more empathetic towards the disabled sibling, (38.1%), showed much more supportive (34.3%) and caring attitude towards the sibling (36%) and improved sharing of their gadgets and toys with the sibling (33.5%) and accepting into the playgroup (23.4%) than pre-pandemic times - shown in Table 1.

Most parents (79%) reported that they themselves noticed changes in their own physical, psychological, and social well-being such as feeling worrying about their child's future (59.8%), feeling helplessness (44.8%), tiredness and exhaustion (29.7%), lack of personal time (28.5%), lack of sleep (18.8%) and reduced work efficiency (18%).

Parents perspectives suggestions on continuing remote rehabilitation during and post pandemic

Parents reported that they recognized the high (70.3%) to moderate importance (16.7%) of continued rehabilitation services for their child. Most parents preferred sessions in the center with social distancing (63%) , the blended approach between online and tele-rehabilitation (28%) and home rehabilitation or no therapy at all (9%). Due to closure of the centers and till the access services in the center,

79.1% of parents reported that tele rehabilitation was the best available option.

The parents were asked to indicate if and in what situations telerehabilitation should be applicable in the future. The responses were if the child was unable to go to the center due to illness (39.3%), not physically being in the country (26.4%) or during a vacation (24.7%) to ensure the continuity of care. In case of online sessions being continued, the parents expressed the need for ongoing training on giving therapies, using assistive devices, technological support, time management and psychological support.

DISCUSSION

The main objective of this study was to explore the experiences of parents of children with disabilities who received remote rehabilitation services, particularly during the lockdown period in the UAE. The survey response rate was higher from Abu Dhabi when compared to the other 6 Emirates. The survey was sent through the centers to the parents as the researchers of this study did not have access to the parents, hence there was no opportunity to check how many parents were contacted by the center within each Emirate.

This study involved mainly families with an average of four children, one of whom were disabled. The mother was the main carer for the children as seen in our study. More than 50% of the parents worked during the COVID-19 pandemic while caring for other children who were at home with online classes, this placed an increased pressure on the parents. During post-COVID times we assume that when the other children are at school, it might be possible for parents to focus much more on their child with disabilities if a telerehabilitation session is offered.

Most children in our study had multiple disabilities, which increased complexities and challenges for parents in managing the children (12) especially with reduced access during the pandemic (13). As most children received therapy from more than one specialty - most receiving Speech and Language therapy, Occupational therapy, and Physiotherapy alongside Special education. These two disciplines are highly hands-on requiring physical strength and variety of equipment, thus carrying out therapy at home proved challenging for carers (14). Even in the centre, most children receive therapy from multi-disciplinary teams, and it is highly challenging to plan this on telerehabilitation sessions. Telerehabilitation for those with multiple disabilities will always be challenging for parents and adherence to it is also highly difficult (15). Hence, it is more beneficial to children who do not have complex issues.

Besides, there was not enough equipment or readiness of parents to provide therapy at home despite getting guid-

ance from the therapists. Nearly one fourth of the participants reported having technical challenges such as difficulty using specific educational programs, internet issues like the study by *Pinkerton et al.* (2022) (16). However, these issues were much higher during the pre-pandemic (17). With the pandemic lasting for over two years, the parents might have learnt to overcome technical challenges, and it will be interesting in future studies to explore the current competencies of parents for accessing and using technologies related to telerehabilitation.

Djuric et al., (2022) reported that various public platforms and social media were utilized in spreading awareness for parents regarding the importance of continued care for children during COVID-19 in the UAE (1). Additionally, most participants in our study reported to have received information and plans prior to online assessment and treatment. The rehabilitation centers engaging effectively in spreading the awareness about the importance of continued care and having provided all the necessary training including safe home environment, technical support telerehabilitation can be embedded into their regular training now in post-COVID times (8, 18).

Our study highlighted the importance of accessibility and maintenance of assistive devices for the child to continue therapy and function effectively at home. Of those requiring assistive devices, only half of the participants reported having access to the equipment or tools. Only a few basic assistive devices were used by the children such as ADL tools, communication aids, mobility, and visual aids with limited access to maintenance services. For some of the equipment such as wheelchairs, although there could have been an opportunity for teleassessment, it is best to get the physical check done at the service center for technical accuracy (19). Accessing assistive devices could be a challenge and this is particularly seen in low and middle-income countries (20). However, in the UAE due to high funding and good infrastructure, access, or affordability to most assistive devices were not a major issue. Although these assistive devices may not be suitable for home use, this opens opportunities for developing suitable home-use assistive devices (21).

The negative effects during the lockdown were not only seen in children but on the parents as well. Some of the previous studies have shown that children's activities and behaviors are directly related to the parents' psychological and social well-being; (22, 23). The anxiety levels among parents or caregivers of children with intellectual and developmental disabilities were very high even during the pre-pandemic with elevated depression symptoms (24). Although our study did not correlate children's activity and behavior to parents' psychological wellbeing, they reported tiredness and were anxious about their child's future. Fur-

ther, telerehabilitation was not a recognized form of treatment by the medical insurance during the first few months of the lockdown in the UAE, might have added to the financial stress (1). Also, many parents were either not working or doing part-time work during the lockdown, further adding to the financial stress. Setting up support groups for parents would have relieved their stress and anxiety (25, 26).

Social interaction for children is vital as it has psychological and therapeutic benefits. These benefits were noticed in the study done by *Cacioppo et al.* (2021) (27). Further, 80% of the parents reported the therapies provided by tele rehab were different from the normal services within the centers and we believe that the deteriorations observed could be the therapies being less effective, and child's lesser engagement during therapies. This could be due to the majority of children in our study being school age; this would differ if the children were of pre-school age, as telerehabilitation (28) was a good addition to home program in a study done by *Sel et al.* (2023) (29).

In the survey, the parents reported that the child was bored being at home during the pandemic - this was in contrast to pre-pandemic as they had lot of outdoor and institution-based activities such as robotics, cycling, hydrotherapy, thus not needing online treatment. This makes a good case for children to physically attend the sessions in the center based on post-COVID times. On the other hand, there are multiple benefits for using telerehabilitation especially when there is restricted or limited access to centers due to illness of the child or parents' (30). Now in post-pandemic times, telerehabilitation can be used as an adjunct but it is not meant to replace face-to-face session (31).

Our study showed that the number of therapy sessions provided was lower when compared to the ones received in the center - not only due to the lack of equipment, but also because certain services can only be provided by trained therapists with special skills. Therefore, if tele-rehabilitation services were to be offered effectively, it is best for therapists to be trained and certified (32). This then means therapists can decide how and what type of interventions are suitable through telerehabilitation (33). Observation regarding the progression during telerehabilitation was mixed from significant improvement to significant deterioration. However, our study could not correlate this to the type of therapy sessions and/or to the complexity of condition, which is one of the limitations of our study. The studies in the future must consider and conduct correlation studies.

Our study showed that the most improvements were seen in communication skills but in the areas that required special therapeutic handling, such as fine and gross motor skills, improvements were to a lesser extent.

In situations where accessing therapy in the center is difficult, effective transfer of therapies from the gym to home becomes necessary. This requires good co-operation between parents and therapists with a well-structured, goal-oriented, individually tailored program based on environment and physical space (14, 34-38).

Most research on telerehabilitation (including our study) during the pandemic employed surveys to capture the experiences but future research should focus on controlled clinical trials. *Hurtubise et al.* (2022) (39) has proposed four-year longitudinal multicentric action research involving training and implementation of family centered telerehabilitation by pediatric therapists. For the blended approach to be effective and successful, the parents or caregivers must be a core member receiving appropriate training. The experiences reported during the pandemic could be reflected on the current and future use of telerehabilitation for children with disabilities (28).

There are no reports of any major safety concerns or any harmful effects on a child's health (8). One fourth of the participants reported not having instructions on safe handling during the telerehabilitation sessions. Furthermore, our study did not consider different types of safety issues such as falls. Future studies can consider this aspect. Clear planning, communication and collaboration between parents and therapists is a key to success for telerehabilitation (39, 40).

CONCLUSION

There has been a paradigm shift in the use of remote rehabilitation, specifically tele-rehabilitation between the pre and post pandemic. Research on its' use for children with disabilities has been increasing since the pandemic when compared to pre-COVID times. Telerehabilitation gained its central position during COVID-19 and there have been efforts to use it effectively by overcoming administrative and technical barriers. Since the pandemic, there have been ongoing efforts in increasing the quality of online services. As remote rehabilitation was a popular means of providing continued care during the pandemic, the time, resources, and funding were allocated towards development and application of it. Telerehabilitation can be in the future used as a blended approach for education and supervised home program purposes and also, when physical access to the center is difficult. Future research should compare the continued use of telerehabilitation and its effectiveness. Also, one of the limitations of our study was that most response was from Abu Dhabi which could potentially have geographical bias and could impact on the generalizability of the results. So, future studies should consider exploring other emirates.

Acknowledgments

The authors would like to extend their gratitude to the Abu Dhabi Statistics Center for assisting in data collection and to Dr. Cathrine Tadyanemhandu & Ms. Ana Anjos & Ms. Dhruvi Mysore for their contributions to proof reading and feedback of this manuscript.

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SAŽETAK

Usluge rehabilitacije za djecu s teškoćama u razvoju tijekom COVID-19 pandemije u Ujedinjenim Arapskim Emiratima: iskustva roditelja

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Uvod: Covid-19 pandemija donijela je promjene u profesionalnoj praksi diljem svijeta. Djeca s teškoćama u razvoju u Ujedinjenim Arapskim Emiratima primala su usluge rehabilitacije na daljinu tijekom razdoblja karantene radi suzbijanja virusa. Ovaj rad istražuje iskustva roditelja djece s teškoćama u razvoju koja su primila usluge rehabilitacije na daljinu tijekom Covid-19 pandemije.

Metode: Istraživački tim je izradio anketu na engleskom i arapskom jeziku. Demografski podaci, karakteristike djece, obiteljske prilike, pristup rehabilitaciji, korištenje pomoćnih sredstava, financijske i psihološke implikacije na roditelje i djecu te buduća upotreba terapije na daljinu. Roditeljima je raspoređen kroz rehabilitacijske centre i analiziran je pomoću deskriptivne statistike s učestalostima i postocima.

Rezultati: Anketu je ispunilo 239 roditelja čija su djeca s teškoćama u razvoju primala usluge rehabilitacije na daljinu uglavnom putem telerehabilitacije. Pritisak i psihološki utjecaj na roditelje bili su visoki, iskazujući frustraciju (44,8%) i anksioznost (59,8%), iako (70,3%) prepoznaje važnost kontinuirane brige za dijete.

Zaključak: Telerehabilitacija je tijekom pandemije bila sredstvo za osiguranje kontinuirane skrbi u UAE. U budućnosti će rehabilitacija na daljinu biti primjerena u određenim situacijama kada je pristup centru ograničen ili nikakav. Buduća bi istraživanja trebala istražiti daljnju upotrebu telerehabilitacije i njezinu učinkovitost.

Ključne riječi: COVID-19; TELEREHABILITACIJA; DJECA S TEŠKOĆAMA U RAZVOJU