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This research examined the experiences of Saudi Arabian families which had an ID during the period of lock downs and social isolation. Mixed methods of research were carried out to evaluate family's response for social and counseling support. The survey showed that no particular change was observed during and after lock down periods. However, the routine of people was modified in the open vicinity. The recommendation based on targeting innovation for social support. New services can provide a direct benefit to people and engage in better quality of life in Saudi Arabia.

Lastly, the prime recommendation to deal with the Families with children with ID would be to turn smoothly to the new routine. Whereas the special lessens and education design can also help to deal with the children with ID in Saudi Arabia.

children with ID. It is crucial for the Government to recognize this and implement measures that can address the issue.

The impact which was highlighted for Saudi People actually utilized the data. Research stated that no impact in counseling and community support was detected from variables. Moreover the logistic regression also displayed a similar result for most of the disable students. Now only one impact can be highlighted for child development. It base on the routine. The evidence is present in the result section where data clearly indicated that community support and counseling session remain the same after and before the period of pandemic and social isolation. The only point which now remains is the routine where either counseling is required or it is sufficient for daily operations.

Overall, this study was able to establish that COVID-19 has had a significant impact on the lives of families with children that have ID. There is reduced access to both counselling and community support, and this continues to have various negative impacts for these families. While the changes brought about by COVID-19 are being addressed by the government, it needs to do more, and identify how it can help specific groups within the population that may each be affected differently by the pandemic.

Conclusion and Recommendations

The concern for careers in Saudi Arabia provides a clear evaluation of risk present in lockdown where the country have feeble ICT infrastructure. The best resolve in this case would be to use online medium for all forms of communication. It would improve the student learning and provide new forms of counseling practice. Saudi Arabia can introduce a pandemic budget to nullify the effect of finance on Saudi Families. A Financial distress can elevate the crisis for the student with ID.

Different kinds of IDs related with language and learning can be deal with specialized professionals. For example, the disability following understanding and comprehension would require open lesson for language. The level of support would depend on the funds available in country.

world to take a more focused approach in aiding the people who are suffering not just from the disease itself, but from the various impacts of the disease on people's daily lives (Kelly, 2020; Armitage & Nellums, 2020).

More importantly, results from this study support the importance of intangible support received by families with children that have ID, such as counseling and social support. These types of interventions were each shown to have a marked decrease due to the pandemic and from the interviews, it is clear that this decreased support does have a detrimental impact on the lives of the families and their children. As established by works such Cudré-Mauroux et al. (2020), Franklin et al. (2019), & Wakimizu et al. (2018), the routines established by children with ID are so important to their development, and as such, drastic departures from this routine can become a significant impediment for their growth. While the lockdown would most definitely restrict access to services around the globe, literature reports on the alternatives to traditional support services available elsewhere which seen increased access during pandemic (Zaagsma et al).

From the interviews, it is clear that while technology is being used in the country in order to help ensure that educational and support progress of the student population is continued, this change has greatly affected the ability of children with ID as well as their careers as they struggled with adaptation. This could be indicative that the online supports existing currently would not be appropriate making current clients disillusioned in their effectiveness. Thus, the current remote support services should be redesigned to regain the trust of clients and to engage potential clients enough to stay with the service. The interview responses also highlighted that there would be no significant issues associated with the technical capabilities of carers, with all of them reporting either already receiving remote help or having no difficulty in trying once it is offered. The use of technology is crucial to enabling children to adapt to a new learning environment (Goldschmidt, 2020; Baurain et al., 2013), but what is working for the student population in general is not as effective for

Overall, most of the respondents indicated alternative services to be beneficial and a good option to have. Some carers who had some exposure to alternative services were firm on low benefit of online support as opposed to life interaction either with professional counsellor or the parent, unless good design of service delivery is implemented.

“Better if we had in person.” “Like I said, I think it is not working as well in terms of counselling support.”

“I think it would be good. They need to design it well though.”

Discussion

The survey and interviews conducted lead to a number of insights regarding how consequences that arose from the COVID-19 pandemic changed the experiences of families that care for a child with ID. First, while the material support from the government that families were receiving was not found to have changed significantly, the ability of families to provide for their needs, as well as the needs of the children in the family who have ID have certainly been affected.

Some of the parents of children with ID lost their jobs to the social distancing measures implemented due to the pandemic. This has affected their ability to provide for the needs of their family, especially for the specific needs of their child with ID. No change could also be attributed to the lack of extra government financial stimulus targeted directly to lower income families which may include families caring for children with ID. The Saudi government COVID-19 fiscal response measures were aimed primarily at supporting employment in the private sector through wage subsidies and other private sector supports. On the other hand, measures implemented on May 10 2020 such as the removal of cost-of-living allowances for public sector workers in conjunction with 10% VAT increase as well as custom duties increases for the wide range of imports (IMF 2021) being regressive in their nature, may have negatively impacted the disposable income of carers which has a flow on effect on the children. This experience is consistent with literature, as well as recommendations for governments all over the

“Yes, she is sadder. I think it is because she was really enjoying school and being with other people and now that is gone.”

The majority of carers interviewed, reported no significant changes to their ability to care for their children during lockdown. However, some indicated that more interaction was required to cheer up their child. It was evident that the lockdown placed an additional time and emotional constraints on some carers which would normally be passed on to professionals. This resulted in some carers reporting increased anxiety and powerlessness to help the situation.

“It is difficult. I try to cheer her up but sometimes it doesn’t matter what I do.”

“I am trying my best to cheer him up, make the extra time at home better for him.”

“Sometimes it makes you feel that you cannot do anything. I feel bad as a parent when that happens.”

“...it’s beyond my control. I want to do everything I can but now, it seems like nothing I can do.”

From the interview it was also evident that most carers were open minded to the alternative care arrangements such as online counselling, stating willingness to try given the opportunity. On the other hand, those respondents who were already receiving online support or know of their friends who do were reluctant to receive it in the future expressing concerns about its merits. This could be indicative that the online support existing currently would not be appropriate, making current clients disillusioned in its effectiveness.

“I think that would be good. As long as we can access it from our computer, we can try it.”

“I don’t know about this for us but for others, I think maybe the online thing may not work for some children? I talk to a friend of mine who also has a child but with more severe with ID, and she told me that online for them does not work very well. I think it is more difficult to keep the child interested.”

“I do not want my child to get left behind but that is what is happening. We are doing as much as we can, my wife and me, but we are also not very good with all of this technology. We are not used to this at all.”

Next theme identified from the interviews has to do with social support. Each of the respondents considered social support, particularly being able to interact with other family members who live in other parts of the country or region as important for both them and their child with ID. The pandemic has affected this aspect of support that they have previously been able to access freely. Less social support was reported by most respondents.

“We used to visit my mother every week and it does both her and (name of child) a great deal of good. Now we cannot do that. We still use the internet to call her but it is not the same.”

“We were supposed to travel this summer to visit my sister and (name of child)’s cousins but now that will not happen. Those interactions are actually very good for (name of child) because it is difficult for him to interact as well with other children.”

Limited social visits of family and friends is the main contributing factor for all but one respondent, who had interacted mostly over the internet even before the pandemic.

“For us it is not very different actually. I think it’s because we are not really very sociable. Our relatives are far away so we have been using internet to communicate with them even before the pandemic.”

The interviews identified limited behavioral impact on children with ID during the lockdown. Most respondents reported no change to minimal change in behaviour. Only one respondent reported some change associated with boredom.

“He does not like it. He gets bored more, upset more. I think it is because he misses school.”

Similar trends were observed with emotional impacts, with few respondents reporting some changes associated with boredom and lack of social interactions.

of traditional services but that they have opted out of out of caution for the sake of both their children and their entire household.

Another common theme related to material support and possible “financial hardship.” Each of the respondents reported that while there is no change in their ability to receive material assistance from the government for their child with ID, their financial situations in general have gotten worse because of the protocols established by the government to control COVID-19.

“It is mostly the same. We receive the same amount and support. But the problem is we have bigger needs now because of COVID, so money has become more difficult.”

“Business is certainly down. I do not know how much more of this we will be able to survive. Hopefully, it gets better, but a lot of damage has been done for certain.”

“I have not been working for more than one month now, and will likely not be able to work for at least a month more. But the bills do not stop, and we need to survive, we need to eat. We are relying on our savings and the help the government is able to bring, but until when? What happens after?”

“We are not able to provide for our child as well as we used to before all of this happens. It really has had a large impact on our lives, on his life as well.”

With regard to their children’s education, the respondents have also expressed concern that the current measures that are being taken to help enable children to keep up with their studies are not well-suited to children who have ID. This “mismatch of response to need” is reflected by the following comments.

“I do not think the online teaching is working for (child’s name). It is much more challenging for him than for other children and this is very worrying for us.”

“My child is very active. That’s his problem. You cannot keep him still, much less make him listen in front of a computer while the teacher is talking.”

“The facility we go to is essentially part of a larger hospital. So, when we go there, we will be at greater risk, all of us. We just cannot risk that”.

The above responses identify lack of information available to careers regarding the safety and accessibility of traditional services. There was also lack of information about online alternatives, where they were available, which could potentially provide counselling services to the children in need of them.

This fear has had a big impact on the lives of the interviewees and their children with ID, particularly in terms of the external support that they need for their children. In the survey results in Table 2 above, there is a clear decrease in the number of people receiving external counseling support, for their child with ID. In the interviews, it was found that the majority of respondents reported less such services received by the child since the lockdowns began. The variety of reasons were cited, some claimed the child did not emotionally resonate to the service online. “It is very different. I think the online system does not work. When we take him to school once a week, it’s much better, but they changed that for our school to online after we got some positive cases for some people in the school.” Some respondents claimed that even though the services started to return to normal they were still cautious of the virus and specifically wanted the online service. “She is getting less counselling now. Especially at the start. We are afraid to go out so we waited until online was available for counselling because of COVID 19. Even if we are allowed, we did not want to go.” One respondent reported receiving less counselling by choice, only doing what is mandatory, as it is ineffective for the child in their view. “It is very different. I think the online system doesn’t work. When we take him to school once a week, it’s much better, but they changed that for our school to online after we got some positive cases for some people in the school.” For one of them, it was found that the facility that they go to was closed following COVID-19 quarantine procedures, and that they could not find a facility that was near enough for them to access. Another two respondents reported that the facilities that they used to go to had begun offering opportunities for them to resume availing

have significant impact on whether or not the household experienced a difference in support before and during the COVID-19 pandemic.

Table 3: Logistic Regression

	Coefficient	SE	Z	p-value
Household Size	-1.522	-0.3825	-0.398	0.6907
Monthly Income	0.00009734	0.0000588	1.656	0.0978
Age of Child with ID	0.1639	0.1794	0.914	0.3608
Gender of Child with ID	0.3839	0.5249	0.731	0.4645

Interview Themes

Ten of the original survey respondents were interviewed. These respondents are parents of children who have ID. This was done to identify and clarify the reasons for the changes in counseling and community support identified in the quantitative part as well as gain more insights into financial situation where the change was not apparent. Additional questions were asked to gain insights of the possible impacts of the COVID-19 restrictions on children with ID as well as their careers.

One of the major themes that emerged from the interviews was the perception of children with ID being at greater risk to contracting COVID-19. While there is no research found that confirms this, the parents interviewed were each seriously concerned about how COVID-19 might affect their children. They correspondingly cite having limited information to base their decisions on as part of the problem.

“I do not know this virus, I am not a doctor but also doctors also do not seem to know much about it, so I am more fearful for my child”.

“Maybe once the experts know more, I will also know more and will be able to decide better for my child. But for now, the best I can do is keep him safe by keeping him home”.

“It is truly a big problem. We want (name of child) to have the support he needs, but we need to also keep him and our family safe. Maybe he does not get sick, but what if he contracts the virus and passes it on to his siblings?”.

Table 2 shows cross-tabulations of the number of households receiving different types of support before and after the COVID-19 pandemic. In terms of material support, no change was found before and after the pandemic. There were 31 respondents or 23.5% who were receiving material support prior to COVID-19 and the same number were receiving support following the response measures put in place after the pandemic. Furthermore, households receiving material support prior to the pandemic were the same households receiving support during the pandemic, further establishing the lack of change in this aspect of support for children with ID.

However, in both counseling and community support, a sharp drop was detected after response measures for COVID-19 were put in place. For counseling support, there were 53 households receiving this support before COVID-19. This is about 70% of the sample. This dropped to 25 or only 33% during the pandemic. Furthermore, the data indicates that the households not receiving any counseling support prior, continued not to do so during the pandemic, and so the drop can be entirely attributed to households that had previously been availing of counseling services not being able to do so during the pandemic. The same is true for community support. This refers to the interaction that household members could make with other people in their community that help them in dealing with the challenges of raising a child with ID. Before COVID-19, 33 (43%) of households were engaging in such support. This dropped sharply to 11 (14%) during the pandemic, which is to be expected, since social distancing measures were implemented, preventing most people from engaging socially with people in their community.

Factors affecting impact

A logistic regression model was built to determine if the demographic factors had any effects on whether a household felt that COVID-19 impacted the support they received in raising their child with ID. In total, 51(67%) of respondents replied that the pandemic had an impact on the support they were receiving. Table 3 shows the result of logistic regression modeling this response. As shown from Table 3, none of the demographic factors considered were found to

Results

Descriptive Statistics

There was a total of 76 respondents to the survey. Some descriptive statistics about the sample are shown in Table 1. As shown in Table 1, the average monthly income of the households surveyed was about SAR 11,000, which is below the median household income of the Saudi Arabian population in Alqurayyat. The average household size is 3.89, which is consistent with two adults and one to two children. All of the respondents surveyed had one child with ID. The average age of the child with ID was found to be 10.71 or 10 to 11 years of age.

Table 1: Descriptive Statistics

	Mean (95% CI)
Household Size	3.89 (3.75, 4.04)
Monthly Income	11,447.37 (10,449.23, 12,445.51)
Age of child with ID	10.71 (10.38, 11.04)

Impact of COVID-19 on different types of support

Table 2: Comparison of Before and After COVID-19

Material Support		After Covid		
		No	Yes	Total
Before Covid	No	45	0	45
	Yes	0	31	31
	Total	45	31	76
Counseling Support		After Covid		
		No	Yes	Total
Before Covid	No	23	0	23
	Yes	28	25	53
	Total	51	25	76
Community Support		After Covid		
		No	Yes	Total
Before Covid	No	43	0	43
	Yes	22	11	33
	Total	65	11	76

The questions in the survey are structured to collect data that can be analyzed numerically.

In particular, the survey measure was designed to gather data on three areas. The first area is on the demographic details of the family. Those demographic details are important covariates to the variables of interest. The second area is on the nature and amount of support that the family received prior to the COVID-19 pandemic. Finally, the third area is on the present nature and amount of support that the family is receiving.

In addition to the survey, some participants who took part were recruited for an interview. This was done with the purpose of further exploring the differences in their experiences before and after COVID-19.

Data Collection

Respondents were recruited based on records from the Department of Education in Alqurayyat. The department keeps track of students that have IDs and have contact information for the heads of their households. This was used as the sampling frame for the study. Invitations to respond to the study were sent to each of the families through this sampling frame. The survey was conducted entirely online with the target for a response rate of at least 20% of fathers and mothers.

Data Analysis

Responses from the survey had tallied. Quantitative analysis was focused on comparing the data from responses made in the context before COVID-19 protocols were enforced with the data from after the protocols began being implemented. Corresponding statistical tools, such as Chi-Square tests for independence, were administered to determine if there is a significant difference in responses between the two contexts. The demographic details gathered were used as covariates in the analysis, in order to determine if the responses differ in terms of each of these demographic details. Qualitative analysis was then conducted by examining the responses from the interviews and drawing out the themes that are common among them.

service delivery such as Telehealth & Digi Contact may be seen as appropriate replacements, softening the impact of withdrawal of people with ID's from traditional support services. This is not without challenges as it is much harder to establish rapport and engage with the new users of the support services using digital technology as indicated by Johnson et.al. (2020).

This study focuses specifically on Saudi Arabia, Alqurayyat city, which is overlooked by current research on the topic and aims to establish whether there were any disruptions in the material support received by families caring for children with ID as a result of COVID 19 restrictions. It is also examining possible changes that may have occurred in the receipt of counselling and community support services by the children with ID during the restrictions. Thus the main goal is to fill the gap in research that exist by comparing the Saudi Arabian situation in these three areas to the situation elsewhere in the world.

Methodology

Design

A descriptive design is used for this study in which quantified data of the survey responses was supplemented with the interview responses from selected group. The main purpose of the interviews is to gain greater insight into the challenges faced by families that care for children with IDs since the implementation of lockdown protocols as part of the country's response to the COVID-19 pandemic. As such, framing the possible experiences of these families based on information identified from literature and determining which of the literature-based experiences are true for the Saudi Arabian population is the direction that is taken. Considering the potentially diverse perspectives of the population of interest, it is important to construct a data gathering tool that is able to capture as many as these perspectives as there are.

Instrumentation

In line with a descriptive design, a survey measure was constructed for data gathering. A survey was selected as the best tool to gather the data necessary to answer the study's objectives.

Armitage & Nellums (2020) discussed the need to ensure that national COVID-19 response must be disability inclusive. As explained by Armitage & Nellums (2020), the COVID-19 crisis disproportionately affects people with disabilities, as well as the families that care for them. Not only do families need to deal with the challenges brought about by COVID-19, but they must also do so while simultaneously dealing with considerable disruptions in the way they care for their family member with ID. Willner et al (2020) found that careers of people with ID received considerably less support from family and friends during COVID-19 pandemic despite higher need.

In relation to the education of children with IDs, Goldschmidt (2020) discussed how resourceful use of technology is needed to ensure that the impact of prolonged school disruption on the education of children is minimized. Different school systems across the world are implementing varying strategies to accomplish this challenge. Children with IDs are especially affected by the disruption, as they are less capable of adjusting to a learning environment that is starkly different from what they have been used to (Baurain et al., 2013). Similar challenges could be seen with the disruptions to the external supports the child with ID is receiving some of which could be through the school system.

Johnson et al (2020) using the survey of mental health practitioners from the UK highlighted that the lack of activities and facilities as well as increased boredom and agitation of service users during COVID-19 pandemic was rated as one of the highest challenges to deal with.

In Saudi Arabia specifically, it has been a growing practice pre COVID-19 to include children with IDs in the general student population and this has been having positive impacts such as more positive attitude and less stereotypes towards children with ID's (Alnahdi 2019). Taking this away clearly adds more burdens both to the students with ID and to their families.

The recent evidence from the USA (Jeste et al 2020) & the Netherlands (Zaagsma et al) as well as the UK report alternative

Literature Review

The importance of an external support system to the wellbeing of families caring for children, with ID is well established in previous studies. Various research provided evidence on the critical roles that social services play in both helping children with IDs directly, and helping their family with the many challenges that they encounter in relation to the care for their children (Cudré-Mauroux et al., 2020; Grant et al., 2003; Franklin et al., 2019; Wakimizu et al., 2018). In particular, social services provide tangible support that is built into the routine of the child and the family; forging a solid partnership necessary to both individual and familial growth (Cudré-Mauroux et al., 2020).. Verdonschot et al. (2009) highlights the importance of the community settings for better social participation of people with mild ID. In a more recent study, Barak-Levy & Atzaba-Poria (2020) found some mediating roles of social services in helping families caring for children with IDs to deal with stress. Similar inputs are found from other works, such as Malik et al. (2017), Robinson & Graham (2019), & Heys et al. (2020). It is therefore clear that suddenly removing the availability of these services can have a severe impact on families with children that have IDs. Such removal is one of the possible consequences brought about by lockdown measures implemented due to the COVID-19 pandemic.

It has been recognized in recent literature that different countries struggle to provide different essential services to its population amidst the current situation. One issue being that some support services typically take priority over others, as a result an area of the provision of the mental health services may become less of a priority as the focus is shifted on keeping hospital wards from getting overrun (Kelly, 2020). Thus, Kelly (2020) argued for the necessity of the introduction of the emergency legislation specifically for protecting public health services that may not seem as urgent but are nonetheless critical to individual wellbeing. Regarding material support for the disadvantaged groups in Saudi Arabia, there was no extra support announced by the Saudi government during COVID 19, as most of the budget measures were aimed at supporting the business community to maintain employment (IMF 2020).

Introduction

ID is originating in the early age and according to the American Association of Intellectual and Developmental Disabilities (AAIDD) is an impairment associated with significant limitations in intellectual functioning as well as adaptive behavior (AAIDD 2021). As a result, it has significant social impacts as it affects the child with ID as well as careers and close contacts (Katz, Lazcano-Ponce 2008). To minimize the issues with social integration and adaptation, the child with ID, usually requires greater participation in community setting (Verdonschot et al. 2009), thus a system of special supports such as material; help for caring family, professional counseling services as well as social supports from extended family and community for the child with ID to interact with would be important.

The quality of life during COVID 19 pandemic has declined dramatically. While the restriction of movements and enjoyment of goods and services had declined for everyone, it was more profound for the children with ID. A number of studies were conducted to explore the impacts of the pandemic on quality of life of the individuals with ID (Jeste et al. 2020) as well as their careers (Willner et al. 2020), (Johnson et al. 2020), with larger global studies being commissioned (Linehan et al. 2020). However, all recently published works in this area focus on USA, UK as well as some European countries and do not include Saudi Arabia in their sample, this study is trying to bridge this gap to see if there are any unique issues impacting the quality of life of children with ID in Saudi Arabia. This is done by choosing to focus on three important areas of support normally accessible to the children with ID in Saudi Arabia in Alqurayyat city: material support, counseling, and community support. The changes to those areas of support due to COVID 19 will be examined to understand possible impacts on the recipient's quality of life.

تجارب الاسر التي لديها اطفال من ذوي الاعاقة الفكرية فى ايام كورونا كوفيد ١٩ بمدينة القرىات

الملخص:

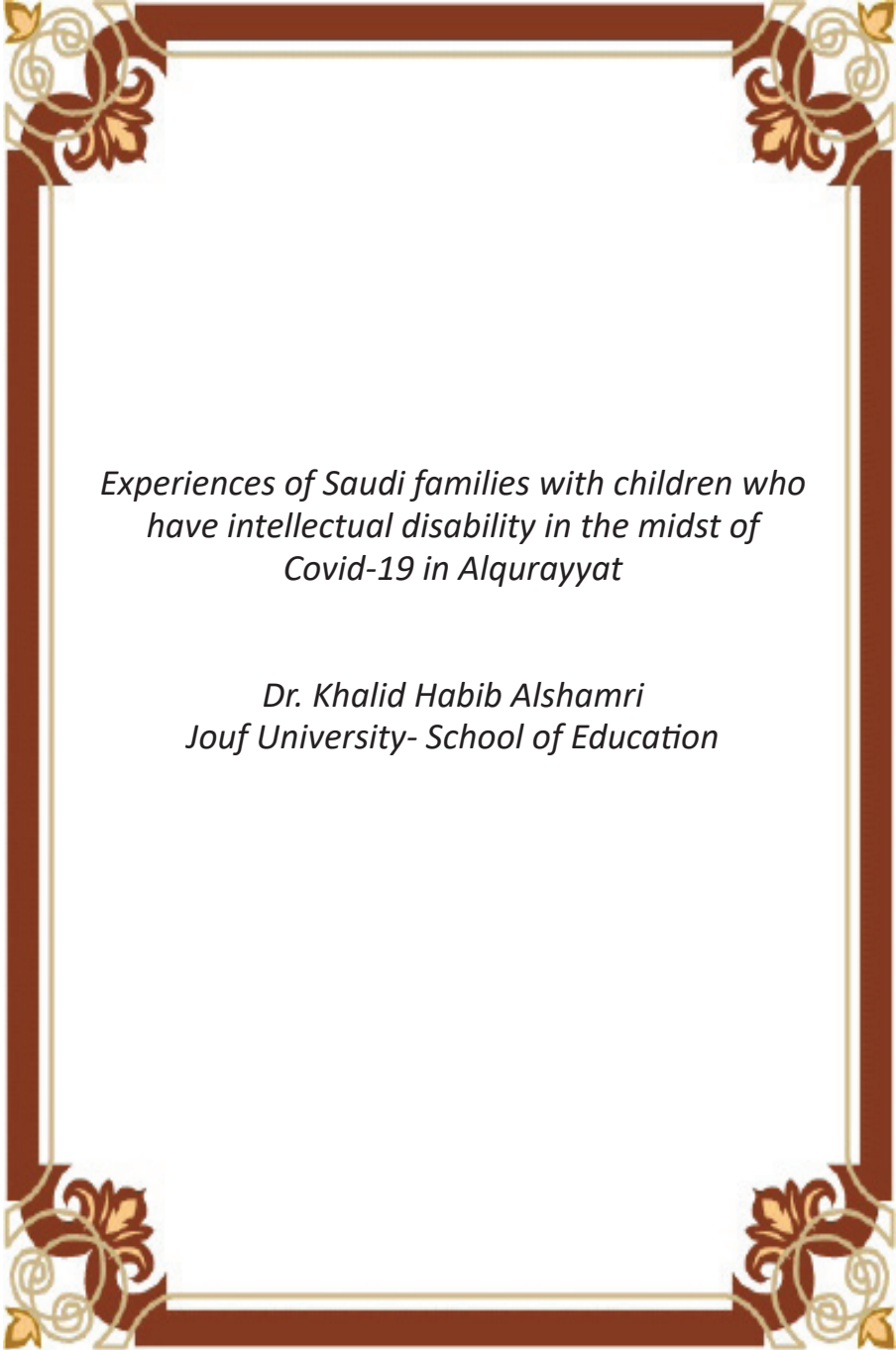
تمت الدراسة بإجراء على الأسر السعودية مع أطفال من ذوي الاعاقة الفكرية في مدينة القرىات خلال جائحة كوفيد -١٩. تم استخدام المنهج المختلط (التحليل الكمي والنوعي) في هذه الدراسة. كان هناك ما مجموعه ٧٦ من المستجيبين تم توزيع الاستبيانات عبر الإنترنت. بعد ذلك تم إجراء مقابلات مع ١٠ من المشاركين في المسح الأصلي. بناء على الدراسة الاستقصائية تبين أن: بينما تلقت العائلات نفس المستوى من الدعم المادي، قبل الجائحة وأثناءها، انخفض كل من الاستشارات والدعم الاجتماعي بشكل كبير. كشفت المقابلات عن العديد من المصاعب التي واجهتها العائلات بسبب إجراءات التباعد الاجتماعي التي طبقت بعد الوباء. تمكنت هذه الدراسة من إثبات أن COVID-19 كان له تأثير كبير على حياة العائلات التي لديها أطفال يعانون ذوي الاعاقة الفكرية. تم تقديم التوصيات المستندة إلى هذه النتائج بما في ذلك؛ أهمية توفير المزيد من الخدمات البديلة المستهدفة، وإعلان عن الخدمات البديلة المتاحة، وكذلك تحسين تصميم الخدمات عن بُعد، من أجل إشراك الاسر وتقديم الخدمات القيمة لهم.

الكلمات المفتاحية: كوفيد -١٩، الاعاقة الفكرية، السعودية، نوعية الحياة.

Abstract

The experiences of Saudi Arabian families with children that have intellectual disability (ID) in Alqurayyat city are examined during the COVID-19 pandemic. Mixed methods approach (quantitative and qualitative analysis) was used in this study. There was a total of 76 online respondents to the survey. Ten of the original survey respondents were interviewed. Based on a survey, it was found that; while families received the same level of material support, before and during the pandemic, both counseling and social support decreased considerably. Interviews revealed several hardships that families had hardships because of the social distancing measures brought by the pandemic. This study was able to establish that COVID-19 has had a significant impact on the lives of families with children that have ID. Recommendations based on these findings are made including; the importance of the provision of more targeted alternative services, informing careers about alternative services available, as well as improving the design of the remote services, in order to engage and deliver value for clients.

Keywords: COVID-19, Intellectual Disability, Saudi Arabia, Quality of life.



*Experiences of Saudi families with children who
have intellectual disability in the midst of
Covid-19 in Alqurayyat*

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