

The Impact of COVID-19 on Parents of Children with Special Needs

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Abstract

Objective: To understand the effect of COVID-19 on parents of children with determination/Special Needs.

Method: A questionnaire with a 5-point Likert scale was developed by a team of psychologists at Kidsheart Medical Center, Abu Dhabi, UAE, to assess and evaluate the effect of COVID-19 on parents of children with determination. The questionnaire was circulated using social media platforms across the world and a total of 44 individuals responded. Majority of the respondents were, however, residents of the UAE. The Statistical Package for Social Sciences (SPSS) was used to run factor analysis and analysis of variance (ANOVA).

Results: Regardless of the diagnoses, gender of the child, age of diagnosis, type of the school the child attends, parents' gender, age of parents, age of the child, marital status, number of special children in the family, parents of children with determination invariably experienced significant levels of stress during COVID -19. Among various types of strategies to mitigate the level of stress experienced by the parents, they found engaging in activities with their children as the most effective.

Conclusion: Parents of children were already experiencing high levels of stress due to the increased needs of their child. COVID-19 has exacerbated the level of stress further as identified in this research. It is therefore important that not only at the Government level but also at a societal level, these parents should be provided with all the necessary support to help alleviate their level stress.

1. Introduction

Although it is impossible for parents to not experience some kind of parental stress at some point [1], research suggests that parents of children with determination experience a higher level of stress compared to those of typically growing children [2-4]. These stresses can vary depending on various factors but are often caused due to the negative stigma associated with their child, availability and perception of social support, and socioeconomic status of the family [5-8]. Hsiao [2] highlighted three

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main factors that are strong predictors of parental stress, which are a) problem behaviors of the child, b) parents' coping strategies, and c) parenting support for families. Coping mechanisms are often used to restore functioning when environmental stressors have overwhelmed our resources. When these coping mechanisms are insufficient to meet the demands, the outcome is usually in the form of stress [9]. Parents of children with determination already find difficulties to come to terms with the news of having a child with special needs. For some parents, it could be a very daunting phase from denial to acceptance and for some, it may take years to be receptive to the term special needs. Once the acceptance comes, then the never-ending process of finding the best possible services begins.

For some, it may come easily but for the majority, it may be a long, constant struggle from long waiting lists to the final diagnosis and subsequently for their turn to be accepted into the services. This may in some cases take years which can be highly challenging for the parents as they may lose the most precious time of the early intervention that a particular child may desperately need at that time in order to make a difference in his/her development. There is no denial in the fact that for these children, every day is crucial in supporting them to achieve their milestones.

With the outbreak of the COVID-19 pandemic, families having children with special needs are facing a greater challenge. This is because these children are not only at an increased risk for exposure to illnesses, but also face disruption of much needed services, exclusion from schools, and other stigma and discrimination [10]. One of the most serious challenges is to make these children understand even the very basic principle of staying away from unfamiliar and strange people. As we know that the majority of these children would not have assimilated the concept of social distancing, one of the prerequisites to stay safe from COVID-19. These children are usually over-friendly, and they may have the tendency to approach strangers with no regard for safety. They are not very familiar with their psycho-social boundaries.

Also, these children require one on one support and anyone working with them has to be in close proximity again negating the concept of social distancing. Hence parents have to be very vigilant about the health status of an individual working directly with the child. This can at times be emotionally and physically quite exhausting. It does not end here, as all schools are asked in some ways to have distance learning and it has been expected that the parents should act not only as a parent but teachers and professionals to help their child. Since most of the children are out of therapeutic services, that can cost them a lot in the long run. Even if these therapies are available, they are only through online platforms which can never be considered as a true substitute to physical attendance.

Also, we understand that routine is very important for everyone and especially more for children with special needs. No doubt that it is very difficult to establish and teach a child with a special need to follow a routine of a daily pattern and once, after very concerted efforts, it is established it is subsequently very hard to change [11].

In fact, research indicates that the child's behavior, rather than cognitive ability, is highly correlated with parental stress [12,13]. Once these children get used to a particular routine, they follow it quite regimentally and any change can upset them and can cause emotional outbursts resulting in them exhibiting unmanageable behaviors that can exacerbate family stress.

The focus of the current study was to explore the psychological effects of the pandemic on parents of children with special needs. We wanted to measure the association of parenting stress with various variables such as the diagnosis of the child, age of the child, gender of the child, etc. We also wanted to check the association between parental stress and variables such as find time for themselves, and adaptation to the new situation. As we know from previous literature, the presence of adaptive coping mechanisms along with social support not only lessens the stress reaction among the parents, but also reduces the stress reaction in the child-parent relationship [14]. Hence, emphasis on such data will not only help to add to our understanding of the current global situation, but also shed some light as to how we can help and support families with children with special needs.

2. Methodology

An exploratory study was carried out to assess the presence and association of stress with other variables among parents of children with special needs. For this purpose, a 39 items questionnaire with a 5-point Likert scale was developed by a team of psychologists at Kidsheart Medical Center, Abu Dhabi, UAE, to assess the following main factors:

- Worries about the child due to the COVID-19 pandemic,
- Parental adaptation to the new situation,
- Parents' ability to find time for themselves,
- Level of parental stress.

The questionnaire consisted of socio-demographic variables including nationality, gender, age, marital status, and employment status. A pilot study was conducted among the staff of the Kidsheart medical center to analyze the feasibility and real properties of the questionnaire.

The questionnaire was subsequently circulated through a convenient sampling method using social media platforms to collect data from participants. It was an anonymous survey, and the participants were informed of strict confidentiality in advance. They were informed that the data will not be used for any other purpose except for the intended research. The survey was distributed a number of times and it was retained on the social media platforms for almost a month to get maximum responses. 44 participants from different countries responded to the questionnaire, including the UAE, India, Pakistan, Egypt, Syria, Afghanistan, Ireland, and the Philippines. Among the 44 respondents, 16 were fathers (36.4%), 27 were mothers (61.4%), and 1 was a grandmother (2.2%).

The Statistical Package for Social Sciences (SPSS) was used to run factor analysis and multivariate analysis of variance (MANOVA).

3. Results

Factor analysis run on the test items identified the following primary factor:

- Worries about the child due to the COVID-19 pandemic,
- Parental adaptation to the new situation,
- Parents' ability to find time for themselves,
- Level of parental stress.

TABLE 1. Profile of Participants.

| <u>GENDER</u> | | | <u>EMPLOYMENT STATUS</u> | | | <u>MARITAL STATUS</u> | | |
|---------------|----|------|--------------------------|----|------|-----------------------|----|------|
| | N | % | | N | % | | N | % |
| Male | 16 | 36.4 | Employed | 32 | 72.7 | Married | 37 | 84.1 |
| Female | 28 | 63.6 | Unemployed | 7 | 15.9 | Divorced | 4 | 9.1 |
| Total | 44 | 100 | Homemaker | 5 | 11.4 | Single Parent | 3 | 6.8 |
| | | | Total | 44 | 100 | Total | 44 | 100 |
| | | | <u>AGE</u> | | | <u>NATIONALITY</u> | | |
| | | | | N | % | | N | % |
| | | | 20-29 | 5 | 11.4 | Emirati | 30 | 68.2 |
| | | | 30-39 | 19 | 43.2 | Indian | 4 | 9.1 |
| | | | 40-49 | 16 | 36.4 | Pakistani | 1 | 2.3 |
| | | | 50 and above | 4 | 9.1 | Egypt | 1 | 2.3 |
| | | | Total | 44 | 100 | Syria | 2 | 4.5 |
| | | | | | | Afghanistan | 3 | 6.8 |
| | | | | | | Philippines | 1 | 2.3 |
| | | | | | | Ireland | 2 | 4.5 |
| | | | | | | Total | 44 | 100 |

TABLE 2. Diagnosis of Children.

| Diagnosis | N | % |
|--|----|------|
| Attention Deficit Hyperactivity Disorder | 9 | 20.5 |
| Childhood Emotional Disorder | 1 | 2.3 |
| Developmental Delay | 7 | 16 |
| High Functioning Autism | 2 | 4.5 |
| Autism Spectrum Disorder | 12 | 27.2 |
| Intellectual Disability | 4 | 9.1 |
| Speech Delay | 6 | 13.6 |
| Behavioural Disorder | 3 | 6.8 |
| Total | 44 | 100 |

The data collected suggests that parents of children diagnosed with Attention Deficit Disorder (ADHD), Autism Spectrum Disorder, Developmental Delay, High Functioning Autism, Intellectual Disability, Behavioral Disorders and Speech Delay are highly impacted psychologically and expressed higher levels of stress due to COVID-19. Only parents of a child with Childhood emotional disorder indicate somewhat reduced stress, however, the data shows that it was a sole respondent and hence would not carry much statistical weightage. This data, however, suggests that irrespective of the type of disability, all parents are experiencing high levels of stress (FIG. 1).

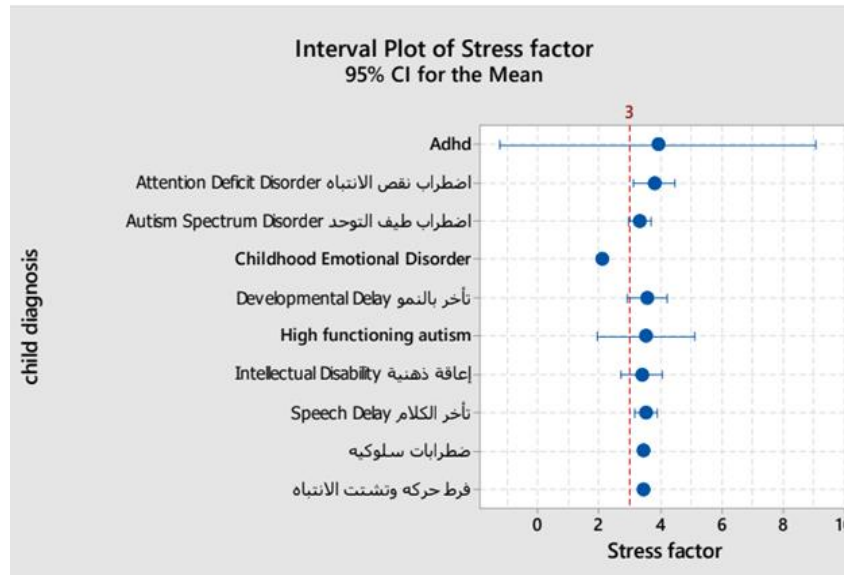


FIG. 1. Interval Plot for Stress during COVID-19 among different diagnoses.

FIG. 2 shows the comparison of parents of children with determination on stress factor. The results show significant differences on how both parents perceive levels of stress, as females (mothers & grandmothers) reported to experience higher levels of stress as compared to men (fathers).

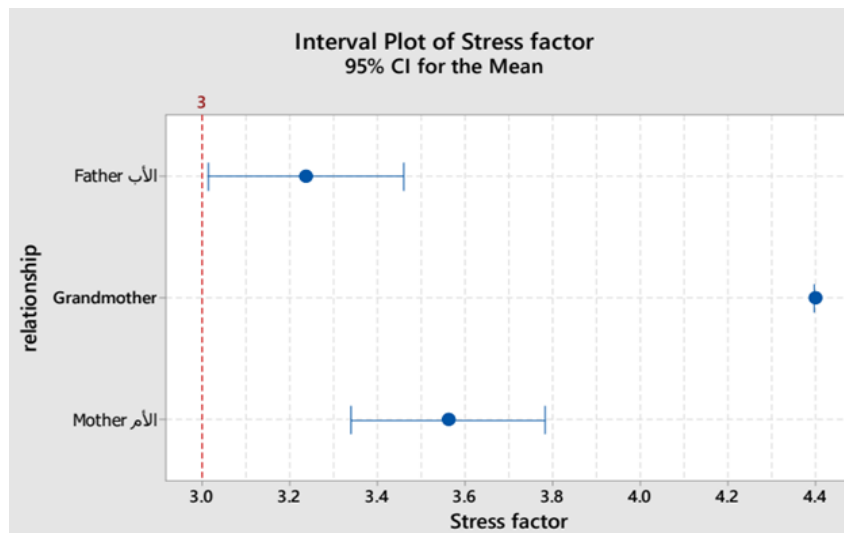


FIG. 2. Interval Plot for Stress during COVID-19 among parents.

FIG. 3 highlights the relationship of the age of child’s diagnosis and parental stress. It indicates that parents of children diagnosed within the age group of 7-8 years were found to be more stressed about the COVID-19 and lockdown as compared to parents of children diagnosed at other ages. In contrast, parents of children diagnosed within the age group of 4-6 years were found comparatively less stressful to parents of children diagnosed at other ages.

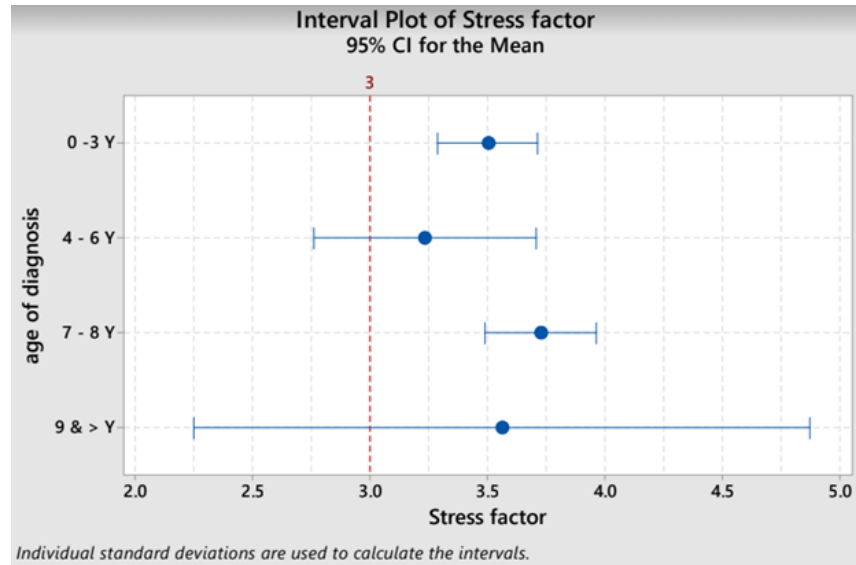


FIG. 3. Interval Plot for Stress during COVID-19 among parents of children based on the age of diagnosis.

Parents of children attending mainstream schooling are slightly more impacted by lockdown and reported to feel slightly more stressed compared to parents of children attending homeschooling and special schools (FIG. 4), although overall they all show high levels of stress with the COVID-19 lockdown.

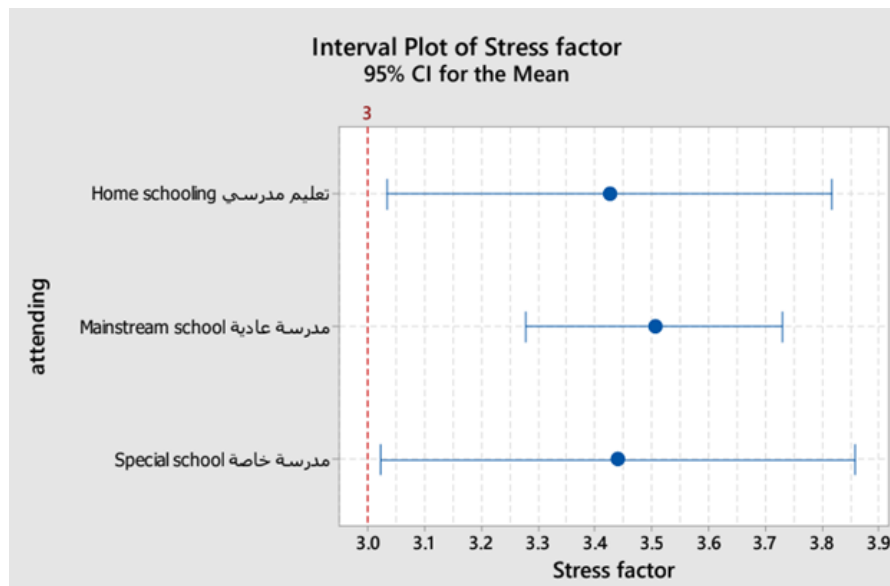


FIG 4. Interval Plot for Stress during COVID-19 among children attending different school systems.

Parents with daughters of determination were reported to be highly stressed due to the COVID-19 lockdown as compared to those with sons with determination (FIG. 5).

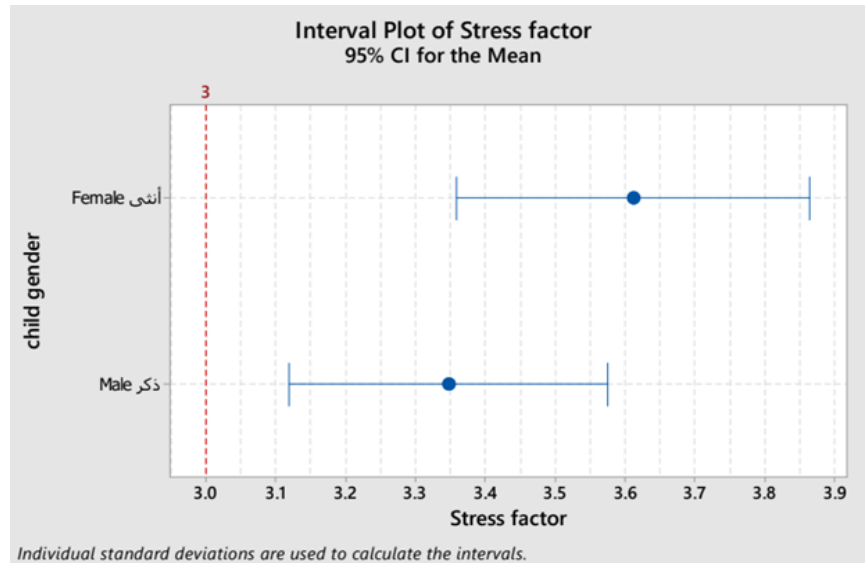


FIG 5. Interval Plot for Stress during COVID-19 among sons and daughters.

Parents within the age group of 50 and above were found to be less worried about the COVID-19 and lockdown as compared to parents of younger ages. In contrast, individuals within the age group of 20-29 were found to be highly stressful when compared to other age groups (FIG. 6).

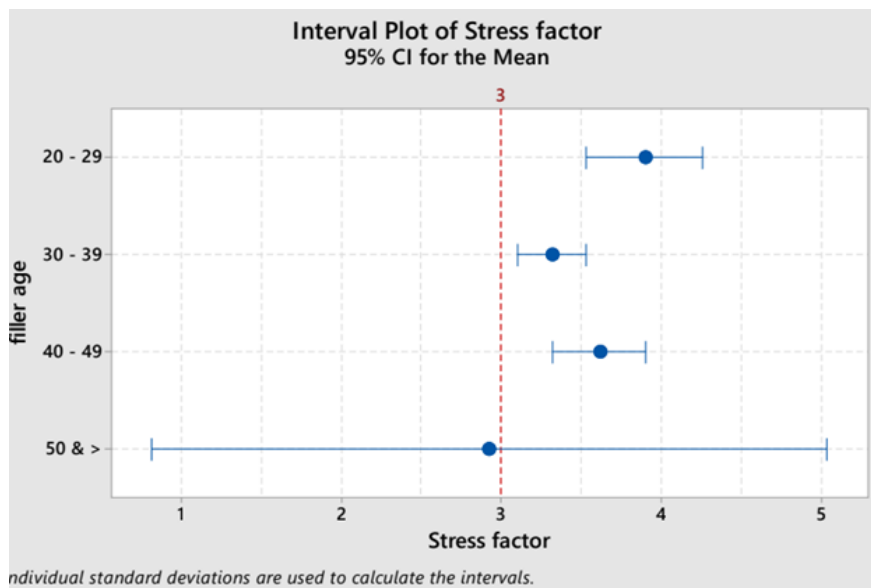


FIG 6. Interval Plot for Stress during COVID-19 among various parental age groups.

Parents of children within the age group of 4-7 years seem to have a high impact of stress due to the lockdown compared to children of younger and older ages (FIG. 7).

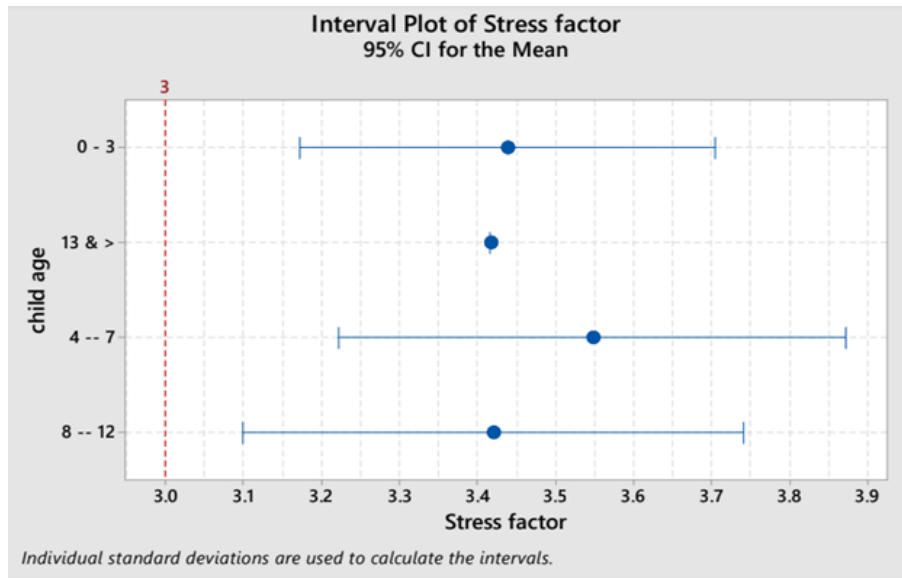


FIG 7. Interval Plot for Stress during COVID-19 among various children age groups.

There is no significant difference among the results for married, unmarried and divorced people as they are equally stressed due to COVID-19 lockdown (FIG. 8).

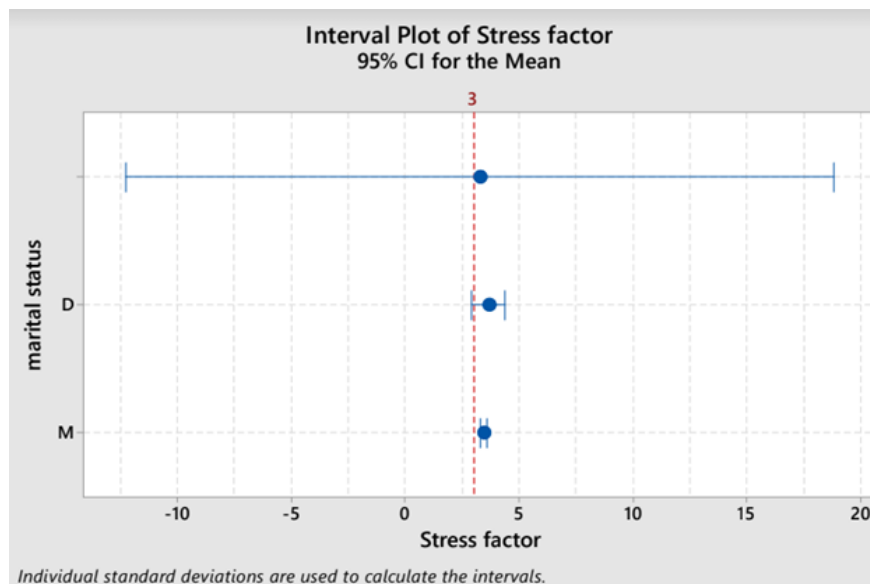


FIG 8. Interval Plot for Stress during COVID-19 among married and unmarried people

Families with two special needs children show a significant level of stress as compared to families of a single or three special need children. Though there was only one respondent from parents having more than 2 children, therefore the results would not make any difference. Also, the questionnaire was completed by the step mother and children were only visiting them on a weekend which was also stopped due to travelling restrictions (FIG. 9).

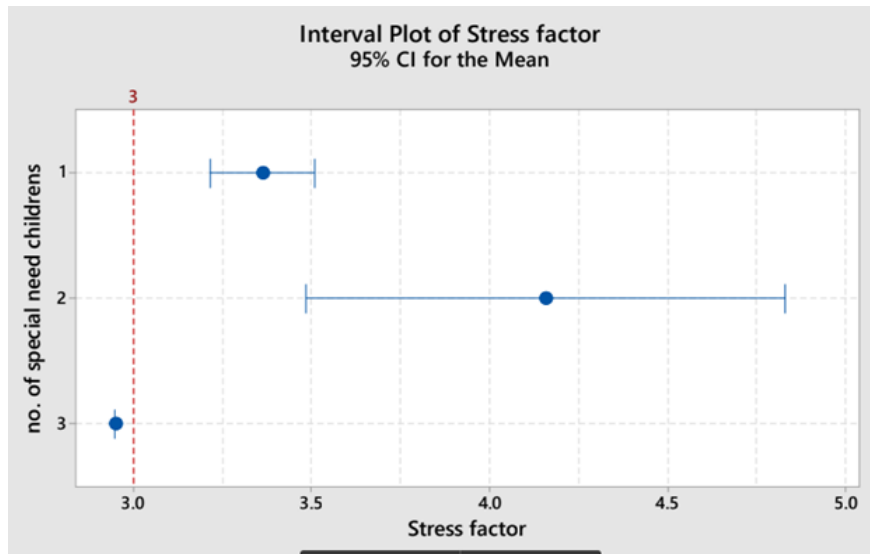


FIG 9. Interval Plot for Stress during COVID-19 based on the number of special needs children in a family

Parents who used “activity with kids” as a stress reduction strategy, showed a significantly lower parent stress level compared to other parents who used other stress level reduction strategies such as Exercise, social media, reading, and ‘me time’ (FIG. 10).

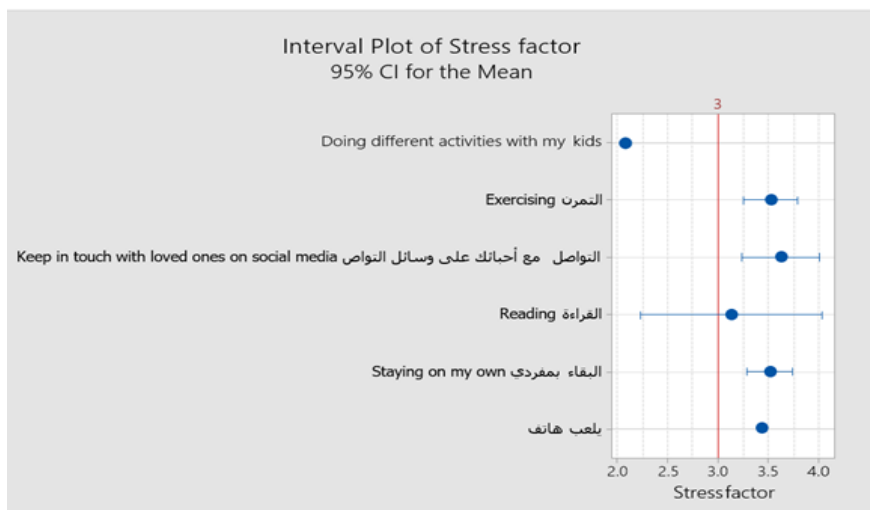


FIG 10. Interval Plot for Stress during COVID-19 based on the stress reduction strategy parents engage in.

4. Discussion

The COVID-19 pandemic has caused tremendous amounts of parental stress globally. The fact that most parents were required to assist their children through e-learning, the closing of parks, beaches and other public areas along with strict restrictions of movement meant that children were constantly at home and thus required more than the usual amount of attention and supervision from their parents. Most parents were already stretched out due to extraordinary demands of work, children, and the home, and this parental stress was expected to be much more among parents who have children with disabilities. Multiple studies have already shown the increase in parenting stress among such parents. As such, several studies have shown higher levels of stress in parents of young children with developmental delays than parents of children without delays [15,16]. In another study, parents of children with Autism Spectrum Disorder have been shown to be experiencing significantly higher amounts of chronic stress as compared to parents of children with typical development [17].

The results of past literatures strongly suggest that the perceived stress level of parents of children with determination is high. However, in our research we examined the factors contributing to the stress among parents during COVID 19 pandemic. The research revealed that the parents of children diagnosed with Attention Deficit Disorder, ADHD, Autism Spectrum Disorder, Developmental Delay, High Functioning Autism, Intellectual Disability, Behavioral Disorders and Speech Delay are highly impacted psychologically and expressed higher levels of stress during COVID- 19. Previous studies also revealed that Parents of children with disabilities often experience a higher level of stress than parents of children without disabilities, regardless of categories of disabilities (e.g., autism spectrum disorders, developmental disabilities, intellectual disabilities, learning [15,17-22]). Along with that, the severity of the symptoms associated with the disorder and the child's behavior problems have been associated with parental stress in a large number of studies [17,23].

It is also found that, among the parents of children with determination, the mothers perceived more stress than the fathers. Former studies also indicated the same results. In a study among parents of children with Autism spectrum disorder, mothers scored higher than fathers in parental stress [24]. A study on children with Down Syndrome revealed that mothers' stress was associated with children's caregiving difficulties; fathers' stress, with children's group status [25]. In a research among parents of children with Autism spectrum disorder, it is found that as a result of women's culturally defined roles, mothers may be less able to escape the domestic sphere, as has been documented with fathers [26]. As a result, mothers experience the impact of their child's disability more directly [26], therefore a greater network of support might be required for them to curb their stress levels.

All the parents of children with determination were found to have significant stress regardless of the age of diagnosis and type of schooling they attend. A study by Hastings & Johnson [27] explored and found no comparative difference in the level of reported stress between parents utilizing the home-based interventions and other parents of children with autism. The research, however, did find that adaptive coping strategies, informal social support and beliefs about the efficacy of the intervention were associated with lower levels of stress. Research also shows that the perceived helpfulness of support has been shown to be an important aspect of its mitigating effect on parents [28].

Parents with daughters of determination were reported to be highly stressed due to the COVID-19 lockdown as compared to those with sons with determination. This finding is supported by a study conducted in the South part of India; it is found that intimacy between parents of girls with intellectual disability was significantly impaired compared with parents of boys with

intellectual disability. Intimacy between parents continued to be impaired significantly after controlling for the confounding effect of challenging behaviors. It demonstrated that parents of girls with determination have more internal difficulties to deal with which may lead them to be stressed.

Parents within the age group of 50 and above were found to be less worried and uncertain about the COVID-19 and lockdown as compared to parents of younger ages. All other parents below the age of 50 were found having stress during COVID-19. Parents of children with determination found to experience stress regardless of the age of their offspring. These patterns support past research showing high parenting stress levels are associated with young mothers and fathers [29].

There is no significant difference among the results for married, unmarried and divorced people as they are equally stressed due to COVID-19 lockdown. In contrast, previous study on the effect of marital status on well-being of parents of children with intellectual disability found single mothers of children with intellectual disabilities to have poorer well-being than co-habiting mothers [30]. Families with two special needs children show a significant value of stress as compared to families of a single special need child. Parents have to take care of both the children and deal with their needs. Greater the responsibilities, their stress elevates. Due to the COVID 19 situation, many of the parents had to constrain their coping strategies within home. They couldn't access many coping strategies they used to engage in. Among the strategies they used, during COVID 19, "activity with kids" as a stress reduction strategy, showed more results in bringing the stress level down for parents compared to other stress level reduction strategies such as Exercise, social media, reading, and 'me time'. By spending time with their kids, the kids might have shown improvement in their skills and behavior, which in turn reduced the stress of parents. And it also helps the parents to feel that they are doing their job as parents and it may reduce their stress. According to the study of Milkie et al, [31] feeling that one spends the "right" amount of time with children is a strong and independent indicator of parents' work-family balance. Achieving it helps them to have reduced amounts of stress.

5. Conclusion

And as they say that there is always light at the end of the tunnel or silver lining in dark clouds, we need to be positive and optimistic. If we analyze this entire time, we can certainly find some positive elements in this pandemic. One of the positive outcomes for the parents of special needs children could be that the parents got the opportunity to know their child a bit more by spending more quality time together. This was only possible when parents were given the opportunity to work from home and this provided them with ample opportunity to upskill themselves in managing their children. The families can afford to spend quality time with their children at home and to engage with them in sharing their favorite activities. This moment in time also became a source of realization to get to know family members more. However, we must acknowledge that at times it may not be possible for the parents to reach out and meet the high needs of a child with special needs given that they have their own busy schedule.

To conclude no doubt that this pandemic has changed our lifestyle drastically and it will take some time to go back to our 'normal life' even if the long-awaited treatment is developed. Everyone is struggling to cope with these changes, but it must be very hard for children with special needs and their families in not only dealing to protect themselves but also to find mechanisms and strategies to protect their children with needs. It is important to put some strategies in place at a government level to alleviate the anxieties of families with children with special needs.

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