

Parental Quality of Life (QoL) in Covid-19 Pandemic and its Effect on Children

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Abstract

Introduction: Literature Search showed that COVID-19 Pandemic is significantly and adversely affecting Mental Health Quality of Life (QoL) of parents, which is affecting children. We wanted to conduct a small pilot study to see, how this interrelationship is panning out for parents and children, where children have Special Needs.

Aim: To analyse how Parental Psychological QoL is affecting Children with Special Needs due to COVID-19 Pandemic.

Objective: To conduct a small pilot study measuring Psychological QoL of Parents having Children with Special Needs, due to COVID-19 Pandemic and how that QoL is affecting their Children.

Materials and Methods: 6 parents are interviewed over telephonic conversation. (1) WHOQOL-BREIF (WHO quality of life, brief scale) is administered and responses were recorded along with (2) perceived stress scale (Google forms format).

Results: All the parents of special needs children reported significant distress and low quality of life specially in environmental domain at this present pandemic situation and expressed severe concern about the disruption of treatment procedure (from offline to online platform) which might hinder the child's progress.

Conclusion: As per the report of the pilot study, reviewing and referencing previous researches and literature in this matter the article concluded that the finding are consistent with the previous researches and studies, the present study exploring various aspects where the parents and the special need children are being affected by the COVID-19 Pandemic.

Keywords: Covid; Quality of Life; QoL; Mental Health; Psychology; Parents; Children; Special Needs

Background

The present article focuses on Special Needs Children in Covid times, looking at their Parents' psychological wellbeing. It explores Covid-19 pandemic effects on quality of life (QoL) of 6 such parents and such QoL's indirect effect on their dependent children. This study includes survey, interviewing parents about their quality of life at the present condition coping with the stresses of a pandemic.

Parents are interviewed and response for quality of life scale and perceived stress scales are taken for quantitative analysis. The reported concerns and mental health condition of parents corresponds with previous study results that parents stress anxiety effects the child's mental health. This study focussed on that aspect for parents of children having Special Needs. In the present study parents reported increased stress and anxiety related to precautions taken to avoiding Covid-19 and change in routines and structures of daily activities due to lockdown. In the literature a single risk factor, such as parental anxiety, has been shown to predict a wide range of negative outcomes among children [1].

Introduction

The novel coronavirus (COVID-19) is an infectious disease that has spread among humans. The COVID-19 pandemic became a major health crisis that has changed the life of millions globally. The WHO declared COVID-19 a global pandemic due to the substantial global-wide spread of the disease affecting many countries [2].

Studies have found that general population are presenting with specific symptoms including chills, cough, dizziness, myalgia, and sore throat, as well as those with poor self-rated health status and history of chronic illnesses have experienced a psychological impact of the outbreak and higher levels of stress, anxiety, and depression [3]. Isolation, social distancing, and closure of educational institutes, workplaces, and entertainment venues consigned people to stay in their homes to help break the chain of transmission lead to distancing people socially [4]. The restrictive measures undoubtedly have affected the social and mental health of individuals from across the world [5]. Under the current global situation, both children and adults are experiencing a mix of emotions, the situation or an environment that is new and can be potentially damaging to their health [6].

As the mental health is getting affected due to uncertainty of the situation and corresponding stress and anxiety the quality of life; an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns is also affected [7]. Researches in this matter showed that the quality of life after COVID-19 pandemic have significantly decreased. Quality of life in this study, that included 70% (81/115) of patients with mild or moderate COVID-19; there was a severe decrease in QoL up to 56% (64/115). Alterations in usual activities and anxiety/depression were present in 59% of patients with a severe decrease in QoL [8]. An online questionnaire survey administered to 359 children and 3254 adolescents aged 7 to 18 years during the spread of COVID-19 in China. It showed 22.3% of youth had scores indicative of clinical depressive symptoms, which is higher than the 13.2% estimated prevalence of youth depression in China. Anxiety symptom levels were also higher after COVID-19 than previously reported, youth who had a family member or friend with COVID-19 had higher levels of anxiety than those who did not [9]. Children's depression, anxiety, and sleep disorder scores were grouped into severity categories [10]. These mental health impacts could be temporary during COVID-19; however, high amounts of stress have been associated with maladaptive behaviour changes, including substance abuse, eating behaviour changes, and excessive alcohol consumption that could persist even after stress dissipates [11,12].

In this condition parents are stressed about their children's development. Children lacks the required social interactions, peer interaction, social play, and physical exercise, outdoor activities for both physical, emotional and cognitive development.

All these compounds, when parents are dealing with a Special Needs Child and this added burden was specifically explored in this study!

Parental mental illness can impact significantly on the lives of dependent children through both direct and indirect mechanisms. Parental factors that may impact directly include the inherited genetic make-up of the child, the intrauterine environment and antenatal

exposure to anxiety or depression, and the risk of direct exposure to the parental mental illness itself. Indirect effects, for example socio-economic disadvantage and marital conflict, which are often associated with mental illness, can also have profound detrimental effects [13].

A recent nationwide poll found that US parents are experiencing higher levels of stress during COVID-19, compared to adults without children, due to extra challenges of managing children's at-home schooling, halts to extracurricular activities, and navigating children's emotions around uncertainty and change [14]. One can only imagine how that compounds in the parents having Special Needs Child.

There is a two-way connection between parent-child relationships and behavioural problems in children [15]. One way describes that children's behavioural problems could predict the tendency or change in the emotional quality of parent-child relationships where parents have to work harder during these parent-child interactions [16]. And when repeated and restrictive behavioural problems are difficult to solve, as seen in some children with Special Needs like Autism, parents tend to be more directive and control by employing verbal or corporal punishments, which decrease closeness and increase parent-child dysfunction [17]. Over time, this not only strengthens behavioural problems in children, but also results in increased mental health problems of parents.

Studies showed that the lack of services has impacted on parents of special needs children and their own welfare and mental health. Though research shows that 46% of parents of typically developing children report having "high" stress during the pandemic, that stress is likely exacerbated for parents of special needs children, who often have to balance being teachers, caregivers, employees, advocates, and therapy providers all in one [18].

The focus of the present article is to discuss the quality of life of parents of special needs children during COVID-19 pandemic and its indirect effects casting upon the children at home.

Method

Both qualitative and quantitative ways of data collection is employed to get a whole picture of the perceived situation by the parents. To take an overlook of the COVID-19 pandemic situation 6 parents of special needs child are interviewed over telephonic conversation. These 6 children are diagnosed with Autism Spectrum Disorder comorbid with Global developmental delay and some even have comorbid ADHD.

WHOQOL-BREIF (WHO quality of life, brief scale) is administered and responses were recorded among with perceived stress scale (Google forms format). Parents are asked about their concerns and effects they noticed due to COVID-19 spared; the lockdowns and the health issues.

Result

See table 1, 4 of 6 parents reported low quality of life mainly in environmental domain in consequences of the threat of COVID-19. 2 parents show average range of quality of life in other domains and reported distress due to the constant threat of being infected. 1 of the 4 parents showed significant stress level and low quality of life in all the domains expect average quality in environmental domain and reported support she is getting from her friends and safety in staying home. 1 of the other 2 parents reported above average quality of life in 3 domains with average score in environmental domain stating that the lockdown created the scope to spend more quality time with their children. All parents significantly reported that lockdown disrupted their routine program which might hinder the child's treatment progress and that is very distressing for them. They are always preoccupied with taking precautions necessary to avoid getting infected and managing all the therapies at home in online platform. 1 parent reported they faced a serious dilemma weather to continue therapies offline or online caused distress but managed coped the situation. 2 parents shared a signification aspect that is their concern about the elder sibling being neglected in course of managing and taking care of the child with special needs. This pilot study have explored the effects of the COVID-19 on varied aspects of the parents of special needs child, the child itself along with their sibling's mental health.

	Domain1 Physical Health	Domain2 Psychological Health	Domain3 Social Relationships	Environmental	Mood Issue (in children)	Sibling Concern
Parent 1	Average	Average	Average	Low	+	+
Parent 2	Average	Average	Average	Low	-	-
Parent 3	High	Low	High	Low	+	+
Parent 4	Low	Average	low	Average	+	-
Parent 5	High	Average	High	Low	-	+
Parent 6	High	Average	Average	Average	-	-

Table 1

Discussion

This pilot study showed a large amount of stress among parents during this pandemic situation which in turn altered their behaviours sometimes. All parents reported increased stress and tension about the accessibility of the therapies for which are required for their children. The parents reported children’s increased irritation to stay at home all day. Two parents accounted that their child remains in a bad mood slighted agitated as they are unable to go out.

Children spending time in a home environment where adults are likely to be more stressed than usual can have an impact on a child’s sense of well-being. According to one study, “comparing the symptoms of post-traumatic stress in parents and children confined in pandemic situations with those of families in normal routines” indicated that “stress levels are four times higher for children who have been in quarantine.” Children living in an abusive home may also be less likely to be identified and supported by schools or social services, simply due to lack of contact with adults outside the home [19].

In previous study on parent’s stress affecting child showed that majority of parents reported, it was difficult to continue parenting in the same way as they did prior to COVID-19, and almost half of the sample reported that parenting had become harder over the course of the pandemic. Commonly reported factors that influenced parenting were changes in children’s daily structure and routines, demands related to children’s online schooling at home and worry and anxiety around COVID-19 [12].

All the parents reported concern about the treatment procedure and efficiency of online therapies. They reported increased stress due to inability to assess therapies and doctor’s consultation as they used to do earlier. In studies it is evident that, parents of special needs children need to continually seek out special treatment, medical equipment, and other services about how to deal with child’s behaviour, which would increase their psychological burden. Parents with child who have diagnosed ADHD reported managing hyperactive child who is staying in home without outside exposure, the scope of channelizing their energy is restricted thus their sleep and other routines are also getting altered a bit, which is distressing for parents too. The pandemic would prevent parents from seeking solutions to deal with the behavioural problems among special needs children [18]. Studied showed that parents reported, disruption in services, many parents have reported that their children have regressed significantly, losing precious milestones and abilities they had, in many cases, worked for months or years to achieve [18].

Parents of special needs children when interviewed reported that concern related to their other children also. Siblings (with or without special needs) of special needs also getting affected as parents anxiety and stress are increased in managing both children in home

and coordinating online classes and therapy sessions. Two of the parents accounted of not being able to give quality time to the other child as they remains occupied with the child with special needs. Studies showed that typically developing elder siblings who experienced high parent-focused parentification during childhood and low current social support due to special needs younger sibling were most likely to report high distress [20]. One of the parents reported that the younger child with special needs can now spend some quality with his elder brother as both are doing their daily courses from home.

Around the height of government closures and stay-at-home orders (May 2020), one-in-five parents reported high stress, while three-in-four parents reported increased parenting-specific stress. Other studies have found that high stress is a common reaction to this pandemic and that parents are experiencing more stress than non-parents [21]. Prolonged periods of high stress may result in substantial mental health impacts including greater depression, anxiety, and reduced quality of life [11].

One parent in the study reported that spending time with family members and children helped them to cope with the distress. Their children are also able to spend more quality time with parents helping them to manage with the distress caused due to lockdown. A study showed, parents, to manage these difficulties, found that doing family activities together, keeping in touch with family/friends virtually, and keeping children on a daily routine in the home environment were effective [12]. It is seen that doing family activities together at home and connecting with family and friends virtually are ways to help with coping, bonding, and providing sociability in an environment that limits social interactions [22].

Conclusion

With regard to the researches and studies in this matter the present pilot study of the parents of special needs children showed consistency. This studied explored various aspects of concerns adding up to the stress and anxiety of the parents and the state of their mental health, quality of life and perceived effects that occurred due to COVID-19 pandemic. This ground work may help to create the insight of the volatile mental health condition of special needs children their parents and siblings due to the COVID-19 pandemic. A study with a larger population may throw light on how best to target intervention for this vulnerable group in the future.

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