

Challenges Faced by Parents and Children with Disabilities During COVID -19

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Abstract

COVID – 19 has caused great changes in all aspect of life which affected all people especially vulnerable group such as children with disabilities (CWD) and their families. It causes the increased burden on the caregivers of CWD and negative impact on child's mobility due to lack of access health and rehabilitation services. Vital factor are to be considered in developing strategic health and rehabilitation plans for promoting better care for caregivers and their CWD during lockdown restriction time. Caregiver facing the challenges with their disabilities such as social, mentally, psychological, financial and physical challenges during the pandemic. Healthcare team plays an important role in pandemic with proper precaution and maintains social distancing and wearing PPE kit, situation getting worse they start virtual reality (VR) OR tele rehab start. After lockdown, clinic and OPD shutdown physical therapist (PTs) struggling to safely provide service during global pandemic, may turned to telehealth service of client.

Keywords: - COVID- 19, Tele rehab, children with disabilities (CWD), Virtual reality

Introduction

Disability refers to the interaction between individuals with a health condition (e.g. cerebral palsy, Down syndrome and depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings and limited social supports).¹ Disabilities are an umbrella term, covering impairments, activity limitations and participation restrictions.² Impairment is a problem in body function or structure. An activity limitation is a difficulty encountered by an individual in executing a

task or action; A participation restriction is a problem experienced by an individual in involvement in life situations. 22% of children with disabilities are in the alternative care system, while 72% are in the residential care. 45% of parents of children with disabilities state that they or their children have experienced some kind of insult, humiliation or harassment due to their child's disability. 24% families, one of the parents had to give up work to care for the child, and parents often encountered lack of support by their employers when it comes to additional obligations related to child care. The quality of health care services is rated as high or of very high quality by 60% of parents, while 32% of parents believe that services are of lo quality and 6% say they're of very low quality. 16 % of citizen and 18% of pupil think that discrimination against group is acceptable. Between 25 % and 47% of children with disabilities have experienced violence.³ The convention of the Rights of people with disabilities

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adopted in the year 2006, defines a disability as: "Person with disabilities include those who have long – term physical, mental, intellectual or sensory impairments which in interaction with various barrier may hinder their full and effective participation in society on an equal basis with others."⁴ According to the world health Organization's world Report on disability, an estimated 95 million children (5.1%) aged 0-14 years have some form of disability. Common issues include Autism Spectrum Conditions, Developmental Delay, Behavioral Disorders and Learning Difficulties. In many countries, these children have rights to be included in mainstream school (2-5). Rehabilitation professionals now deliver a wide range of approaches to support early intervention and prevention for children with diverse needs. COVID-19 has lost everything in the world, according to the world health organization,⁵ this virus is a causative agent that affects humans and transfer from one person to other with different symptoms so everyone is advised to take precaution making a social distancing and wearing a mask. The pandemic led to greater changes in all aspect of life, patients with chronic disease and person with disabilities and their families.^{6,7,8}

Causes:

There is the numerous cause of disability. Unfortunately most of the instances avoided with proper prevention, disability are mainly caused by:

- Genetic problems
- Disease (Polio for example)
- Malnutrition
- War (particularly through anti- personal mines)
- Sanitary neglect
- Poverty (which is often followed by the following mentioned causes)

Consequences

Social marginalization

A disability of a child is often followed by his being marginalized in the society. For example, it is found that only around 2% of the disabled children have access to education. It is often established in the collective conscious that a disability is a curse or a punishment.

Violence

There is an increased risk of disabled children becoming unfortunately victims of violence due to their inability to defend themselves. Thus, physical, psychological and emotional violence happens to be a sad reality that disabled children undergo in domestic, institutional as well as social circles.

Discrimination due to disability

Discrimination due to disability is numerous: in field such as education, lodging, transportation and cultural life, most of the places and services concerned are largely inaccessible to individuals suffering from disabilities. The obstacles are numerous, be it physical, institutional. Even in developed countries, one could observe a certain discrimination which affects disabled children: they are most often separated from other children, kept in special institution away from the family, in special classes, etc. thus, the opportunity of integrating into society and later finding it becomes impossible.

Material and Method

We had collected the research paper from the year 2019 to 2021 in the study. The latest work in which they have focus on only the children having difference developmental disabilities. All the research paper gathers from Indian studies.

Finding

When there was COVID-19 Pandemic studies have shown that how parents of disabled children and children themselves suffered mentally, socially, psychologically and financial affects. Despite of having all facilities health care and health care providers were not able to provide their essential services and themselves suffered huge loss by getting infected and losing their peers while fighting the battle with COVID -19 Pandemic.

Challenges faced by the children in pandemic

The COVID-19 pandemic poses a serious risk to the well-being of every child, but those with disabilities face multiple threats because of the challenges they already face in their lives⁹. Disable children need health, education and rehabilitation service to improve the individual functional performance depending on their physical, psychological or otherwise health status. Complementary efforts of a rehabilitation team , schools , patients and caregiver to prevent complication , improve functional performance .COVID – 19 has changes th different aspect Of caregiver and children with disable ,most caregiver face difficulties dealing with children and how to manage at homes and how to taken precautions.¹⁰¹¹

- Children with disabilities, they are at higher risk of complications and death as a result of COVID – 19 infections.

- Children with disabilities are also one of the poorest groups of people in the region, which makes them more vulnerable to the impact of COVID-19 infection, as health services are not sensitive to the needs of children with disabilities. These children may also miss out on crucial message about the pandemic and how to protect them as information is not always accessible. Children with disability may also have difficulties complying with the measures introduced by governments. Lockdown and other

restrictions have a disproportionate impact on children who rely on essential treatments and services, as well as support at home such as personal assistance. For many children with disabilities, COVID -19 will only add to the environmental barriers that already hamper their mobility and inclusion.

- Children with disabilities are excluded from current education programmers and there is a lack of consideration for their needs for accessible materials, talking calculators, text magnifiers, modified keyboards, audio books and other devices, as well as additional support from teachers to participate in learning.

- Children with disabilities already face greater risks of exploitation, abuse and violence than other children, as well as institutionalization and separation from their families. As COVID-19 adds to the stresses and pressures on families and communities, these risks are intensified.

- Persistent prejudice, stigma and discrimination heighten the challenges children with disabilities face to participate, make their own decisions and to contribute to the COVID – 19 responses.

Challenges faced by the parents of children with disability

Parenting is always challenging, but the challenges reach new heights when you are parenting a child with special needs.¹² Physically, caregiver of children with disabilities they may experience negative physical health due to increasing physical loads that will cause musculoskeletal disorders, exhaustion and fatigue¹³. During the pandemic situation, level of care of the children also affects the mentally, physically, psychological and financial. Some families have lost their job during pandemic it also has greater affects that led to the accumulation of increasing the expenses of their children.

Accessibility for special Needs

Unfortunately, many families are faced with a world that isn't accessible for their child needs. From ramp access, lack of adequate toilet provision like changing places toilets, narrow or uneven footpaths - list is endless.

Empathy and understanding from others

So many families are faced with a lack of understanding from others when it comes to the challenges of raising a child with special needs. It might not understand your child's behaviors or sensory issue.

Finding places to go on vacation

Coping with the special needs of your child whilst away from the home can be difficult. Factors like travelling distance, finding accessible accommodation as well as activities that your whole family can enjoy can be really challenging.

Adapted clothing and other disabilities Aids

It can be difficult for parents to find adapted clothing to suit their child's needs. This clothing isn't sold in supermarket or clothing stores, but it can be bought online. From seamless socks to incontinence swimwear and bandana bibs.

Behavior issues

Children with special needs may not respond to traditional discipline. Diagnose like ADHD and Sensory Processing Disorder (SPD) require specialized strategies that are tailored to their specific needs. behaviour issue can increase the risk of problem at school. As a parent you will need to be flexible, creative and patient.

Communication:

Communication is a huge challenge for parents

whose children have communication difficulties. They might have selective mutism, be completely non-verbal or have behavioral or sensory issue that affects the way in which they communicate.

Challenges faced by the physical therapy during pandemic

The US COVID-19 shutdown in March 2020 left many physical therapists (PTs) struggling to safely provide service during global pandemic, many turned to telehealth for service (1). Prior to the pandemic, 2% of more than 5400 physical therapy providers in the united states reported providing telehealth service; by July 2020, this percentage increased to 47% (1). In private practice children are largely seen in the community; in their homes, nurseries, schools, clinics or resident care. In the lead up to lockdown, practitioners in all areas were experience similarities. Family were increasing making the decision to stop their children attending sessions at clinics, group sessions, home visits, withdrawing their children from school or taking them home from residential settings for individual and varied reason; for example, fear of the impact of COVID-19 on their child, other family member and general uncertainty.

Once lockdown occurred, physiotherapist in all areas of private ceased face to face contact with clients, verbally with each client and others sent out formal emails notifying why treatment had to cease at present and no contact could be maintained via tele therapy. Most practitioners, unless still employed by schools, had a drastic income drop and suddenly had to navigate what financial options were possibly open to them for example business grants, rate relief, bounce back loans, mortgage breaks, deferring loans, rent holiday on equipment, vehicles and so on. All face-to-face therapy ceased and contact was maintained with clients via Zoom to support them regularly or check in on programme sessions and adapt as necessary. Face-to-face clinic and school

based work had enabled connection with colleague, joint working with shared children and running multi-professional groups, this is greatly missed.

Discussion

Researcher does the survey of over 300 parents and he found the significant adverse impact from COVID-19 on the health and well – being of children with neurodevelopmental. Two – third of care givers reported that their children’s NDD symptoms and comorbid mental health conditions had worsened. Social and emotional well – being were also impacted for close to three–quarter of children, with a substantial proportion of care givers reporting that the restriction were stressful for themselves and their children , almost one in five they took more medication during the COVID-19 pandemic. The impact of COVID -19 and the effects of home confinement appeared to be disrupting children’s routines, which in turn was contribution to reduce sleep quality , a poorer diet , reduction in exercises and increase in time spent engaging in social media and TV. As a response to COVID-19, many service providers had made a rapid transition towards the telehealth service and found that low care giver ratings of effectiveness, satisfaction, and practitioner confidence with telehealth services received. This is essential that there service delivery for children and families , especially in lockdown it includes providing families with technological support , training of practitioners in the effective use of telehealth service for children With NDD, and ensuring safe face- to face models of care hen required. Almost telehealth service focused on strategies for helping care givers establish routines, improve child sleep, diet and exercises and limit screen time, along with behavioral parent management strategies for managing challenging behaviors.

Conclusion

During the outbreak of COVID -19, Parents of special needs children suffered mental and behavioral

problems, together with parenting stress and social support, which influence their stress anxiety. These findings can be used to develop relevant psychological intervention to improve the mental health of vulnerable group during a pandemic COVID- 19. Therefore, the whole society should pay more attention to the parent of special needs children to help them get through this difficult period better.

Overall the studies have been shown that financial, social and psychological challenges facing by family caregiver of children with disabilities have increased during the COVID-19 pandemic. The pandemic caused by a negative impact on the child’s mobility accompanying a lack of access to health and rehabilitation services. Vital factor are to be considered in developing strategic health and rehabilitation plans for promoting better care for caregiver and their children with disabilities during lockdown restrictions.

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