CHALLENGES ENCOUNTERED BY THE INSTITUTIONAL CARETAKERS OF CHILDREN WITH SPECIAL NEEDS DURING COVID-19 PANDEMIC

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ABSTRACT

Background:

The institutional caretakers for children with special needs experienced various challenges during COVID – 19 Pandemic lockdown period.

Aim:

This study analyses the challenges faced by the caretakers of the children with special needs in institutional care during the COVID-19 Pandemic lockdown situation in Bangalore, India.

Methods:

This research followed the case study method to get a deeper insight into the quality of services provided by caregivers in institutions to support children with special needs and their challenges during the covid-19 pandemic. The study was conducted during the containment period of the COVID-19 pandemic situation from April to September 2020 among 14 caretakers from Government and non-government residential homes for children with special needs.

Results:

The challenges vary with care takers who were providing services to children with special needs in the institution and family. The care takers were overburdened due to their dual role to perform with children and parents.

Conclusions:

The study recommends strengthening the government system to facilitate the stakeholders of children with special needs for their wellbeing during any emergencies by engaging more professionals. Stressing the enhancement of the capacity of the parents is significant in any crisis.

Keywords: Children with special needs, caretakers, residential care, COVID-19 pandemic

Source: There is no external source of funding to conduct this study

Word Count: 2223

Declaration of Conflict of Interest
The Authors declare that, no conflicts of interest with respect to the research, authorship and publication of this article.

I. INTRODUCTION

The Corona Virus Disease (COVID-19) outbreak has posed a very serious Public health challenge across the globe, including India. There is a cumulative impact on every foundation of society. This condition is associated with people and their issues as the spread of infection rises exponentially comparative to population concentration. The COVID-19 Pandemic first case was confirmed in Karnataka on 9th March. COVID-19 has turned most of the professions in the city to resume their work from home. However, health professionals, police were outside to provide their service and being on foot for any upcoming emergency needs. But the individuals who have been working hard and their work were going unnoticed were many and Caretakers in child care institutions were one among them.

Home and family provide a protective and nurturing environment for a child's physical, mental and spiritual growth and, therefore, it is considered the ideal place for every child. But not all children are blessed with this ongoing care and protection from infancy through adulthood. Various psychosocial aspects of children with special needs require expert care and therapy becomes inevitable. Children with special needs include locomotor disabilities, mild and moderately hard of hearing, visually impaired children, the mentally handicapped educable group (IQ 50-70), and children with multiple disabilities. Residential care is one of the strategies used to provide quality care for children with special needs and it is still widespread in many countries, including India. However, previous literature mentioned concerns about institutions about their lack of capacity to replace the family in terms of services. Residential care settings generally do not meet the conditions of the expected average environment. Depending on the age of the child, the expected average environment encompasses a range of development-oriented activities, protection of constant care, a supportive family, as well as socialization, and open opportunities for exploration. Environmental control plays a significant role in the development of a child.

The quality of relationships between the child and the caregivers is shaped by the interactions with individual children. Therefore, the emerging relationships between caregivers and children reflect group characteristics and dynamics [1]. The families who have placed a child with special needs in a care institution experience both psychological and physical absence with the child. When the child is in the institution refers to the physical absence of the child from the family and they are incapable to communicate with the child in special needs and their necessities. Inconsistency in raising the child with special needs along with other siblings of the child by the family members is a concern [2].

Children with special needs experience difficulties in their emotional and developmental difficulties in all environments they interact. Family plays an important role in children’s lives and contributes specific attention and experiences in the development of children. Internal and external factors of a family also influence Child’s psychological and physical health [3]. The responsibility of protecting children is a generational commitment. However, institutional care increased when the number of working women increased. The challenges in Institutional care include a lack of sensitive and child-focused care. Many children are neglected emotionally and physically in institutions. The training needs of the caretakers comprise psychosocial support to children and their requirements [4].

The purpose of this study was to provide a deeper insight into the quality of services provided by caregivers in facilities to support children with special needs and their challenges during the covid-19 pandemic.

II. METHODS

A qualitative approach with a case study method was applied to collect data from a sample of 14 institutional caregivers of children with special needs from Bangalore, Karnataka, India. The study was conducted during the containment period of the COVID-19 pandemic situation from April to September 2020. The results of the study unfold various challenges for caregivers of children with special needs who were staying in institutions and who were sent with their families due to the lockdown.

III. RESULTS

Challenges of the Care Takers where children with special needs stayed in the institutions during the COVID-19 pandemic:
The major constrain was the lack of funds. The institution did not receive adequate funds from the agencies as well as the government due to the sudden financial crisis due to the unforeseen situation. This affected the daily routine processes to maintain the well-being of the caretakers and children. The fear of COVID-19 among the workers as well as the volunteers regular to the institution affected the routine activities for the children. The various activities were managed by a group of volunteers from outside and the volunteers who largely depended on public transport could not put their services into the institutional work due to lack of transportation.

Children with special needs are at higher risk. Caretakers of children with special needs who stayed in the institutions were burnt-out with the workload, stressed to keep children safe, and discovering new programs to engage children in 24 hours. The routine work of the caretakers became tousled and complicated during the pandemic period. Subsequently their limited exposure to the reality around them and lack of awareness of the severity of the COVID-19 pandemic, the pressure was enormous to engage them during those days. Caretakers were overloaded with teaching and preparing children for protecting them from the pandemic, managing their problems, and keeping children out of restlessness. This pandemic was an unexpected blow that turned out to be very dangerous and it was a challenge to keep children engaged throughout the day with innovative ideas, creative storytelling, and games due to limited space to move and play.

It took several weeks to understand the gravity of the effect of pandemic and to get prepared to face the same. The children with special needs were restricted on outdoor activities and pressurised to maintained social distancing. The hygienic practices were a staggering task with children with special needs. Caregivers took care to implement a creative calendar to keep them engaged in activities like artwork, study, cooking, reading, and institutional activities. They took initiatives to improve institutional facilities for indoor play, conducting cultural programs, and scheduled time for regular yoga classes and exercise. The guards also joined in yoga classes to overcome stress levels.

Challenges of the Care Takers of institutions where children stayed with their parents during the COVID-19 pandemic:

Caretakers who sent children home faced the inability of parents to provide services to the child with special needs. Caregivers were contacting and guiding the parents over the phone for each child at home. The challenges children face at home include discomfort at home, lack of activities, isolation from the outside world, lack of medical, physical, and personal attention from parents, lack of parenting skills to extend required therapies to the child, inability to provide nutritious food and maintain hygiene at home. Many parents were dreaded of infections, could not prevent children from playing outside their homes, and faced restrictions in bringing the child back to the institution to get proper care from the caretakers.

Another factor of concern was parental economic constraints due to the loss of seasonal occupation during the pandemic. The parental illiteracy and restricted movements to get a new job were pounced chaos in their families. Those parents used to call for economic support which was impossible to provide during the lockdown and limited movement and restrictions. The difficulties of the children who stayed with their parents were cascaded to the caretakers who were in the institutions. These challenges made the caregivers' work multiplied, made their daily routine dropped with complications.

IV. DISCUSSION

The study results reflected the challenges faced by the caretakers in the child care institutions during the COVID-19 pandemic situation and its advantages and disadvantages accompanying each other. The differences in the two-environment echoing the relationship between caretakers and parents, parental capabilities to care for the special needs of the child, and the need to intervene the active parents in the child's life.

The study shows that caregivers confirm themselves as expertise in managing the issues of the children with professional support. The challenges faced by the caretakers in the two environments check out to interrogate whether parents and caregivers are capable of managing the issues of children with special needs. The more involvement with efficiency more the protection to children [5]. Regardless of the two different environments to the children with special needs, the participants of the study mirrored the parental attitude and the relationship with them were the reliable gauges of quality of care to the children with special needs [6]. The difference in the adaptive behaviour of the caretakers and parents largely influences the support required by the children with special needs [7]. The parents lack adequate understanding about their Child’s anguish indications, where a trained caretaker could intervene professionally
The study reveals the significance of parents who can interact perceptively and correctly to the emotional needs of the children through spending quality time with their children with special needs [8]. Parents must realize the fact that the family stress will not reduce if the child sends to caretakers in the institutions [9]. Parents need to learn their children’s emotions and behaviour to build them to grow as human beings within their vulnerable conditions [10].

V. CONCLUSION

The home remains the center of children's lives even when children spend a lot of time in the institutions. The interrogation here was, whether institutions can completely replace the family in terms of service arrangements. The results of this study show that high-quality care is essential for a child with special needs and that it is time to give expert training to parents to become a special caretaker for their children. Parents need to stand-in to respond carefully to the needs of the children. There is a need to intervene with parents to increase their knowledge, skills, and confidence in the management of their child with special needs. Similarly, the Department of Women and Child Development can bring a new policy to strengthen the facilities for stakeholders of children with special needs. Especially for their well-being in emergencies by hiring more professionals for children with special needs.

REFERENCES