

Study of Caregiver Stress Syndrome Amongst Parents of Children with Special Needs as Compared with Typical children.

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Abstract: Research into the families of children with disability maintain that parents or caregivers seems to experience higher level of global stress than parents of children without disability. The aim of the study is to see the level of stress amongst the parents of special needs children and to provide them with support and help to reduce the level of stress. For this purpose, a comparative study was undertaken. The convenience sample included 26 parents of children with different disability and 26 parents of normal children. The instrument used was Parenting Stress Scale(1995). Data was collected from normal school and institutions that support people with disabilities. T ratio was applied on the data and results also proved that there is a significant difference between the stress level of parents of special needs as compared to the parents of normal children. Thus, we need to look forward to look for the levels of the stress and measure to reduce the stress amongst the parents and provide them with remedial ways to manage the stress.

Keywords: Stress, Caregiver or carer, Parents, typical children, parents, caregiver stress syndrome (CSS), children with special need (CSN)

Introduction

Stress is a mixed feeling of emotional and physical tension. In everyday life stress is a feeling that people have when they are overloaded and struggling to cope with demands. According to annual survey conducted by American Psychological Association (APA) average stress level in the united states rose from 4.9 to 5.1 on a scale of 10 in 2015. The main reason given were unemployment, money, health, children and family. The stress associated with caring for chronically ill family member may result in stress for the caregiver. The demand of caregiving can be over whelming especially if you feel that you are in over your head or have little control over the situation. While caring for a loved one can be rewarding, it also involves many stressors. And since caring is often more or less a long term challenge the emotional impact can snowball over time. You can face years or even decades of caregiving responsibilities. It can be particularly disheartening when there's no hope that the family member will get better or if, despite your best efforts, their condition is gradually deteriorating. Not only the families of the child suffer economically and emotionally, caregivers themselves may face serious health and social risks as a result of stress associated with continuous caregiving. 3/5 of family caregivers age 19-64 surveyed recently by the common wealth fund reported fair or poor health, on or more chronic conditions or a disability compared with only 1/3rd of non-caregivers.

In United States there are approximately 61.6 million people who are caring at home for family members including elderly parents and spouses, and children with disabilities and chronic illness. Without this home care, most of these cared for loved ones would receive permanent placement in institutions of health care facilities at a greater cost to society.

Caregiver: A caregiver is someone who is actively engaged in providing care and needs to another such chronically ill, disabled or aged family members or friend. Caregiver is a person who cares for someone who is not able to take care of himself. An individual family member or guardian who takes care of child or dependent adult. The word carer or caregiver comes from the word "Carian" to feel concern and also to grieve.

A slooped whitehaired doctor touched my shoulder and gently asked "Has anyone spoken to you about your son's development". In that moment, in a hospital room long ago, I turned from being a new mother into a lifelong caregiver. Throughout the years of my son's life, the identity of caregiver has pulled and pushed me like tides ebbing and flowing. Now I was a caregiver on the warpath. If your child has a serious illness the caretaking that falls to you is undoubtedly intense. But of course, you do it

willingly. After all you would do anything for your child including switching places in a minute if only that were possible. Instead you give all that you can in every other imaginable way. It's harder than anything you have ever done and honestly these are moments when the sheer magnitude of what you are up against is so overwhelming that you just want to run and hide. Caregivers dilemma is when you are caregivers of an ill/sick/disabled child, it can feel as if the whole world is on your shoulders. Your sick child needs you. You may have other children who needs you, your spouse needs you. Your job however pointless work might seem now needs you, yet there only so much you can give before you will feel mentally, emotionally, and physically drained.

Caregiver syndrome or caregiver stress is a condition that strongly manifest exhaustion, anger, rage or guilt resulting from unrelieved caring for a chronically ill patient. Almost 66 million Americans are providing care to those who are ill, aged or disabled for an average of 39.2 hours per week. Over 13 million caregivers provide care for their own children as well. Caregiver syndrome is acute when caring for an individual with behavioural difficulties. Caregiver syndrome affects people at any age. Caregivers have to be so immersed in their roles, with day/night hours, they often have to neglect their own health. Since their roles are changing from a partnership or mother/daughter, mother/son etc relationship to a caregiver and patient relationship. This role change is difficult for many people to make causing them to experience anger, resentment and guilt. In addition to the psychological and social impacts of caregiving, fulfilment of caregiving role can also have a significant impact upon the caregiver's ability to work and the family's financial wellbeing.

Review of Literature

A study done by Mita Majumdar et. al. (2005) in India found that parents of children who were mentally retarded has higher level of stress than parents of children with normal intelligence. Raj Kumari Gupta and Harpreet Kaur (2010) did a study in India where they found that parents of children with intellectual disability experience more stress.

Nisha Vidyasagar and Susan Koshy did a study in India in 2010 found out that the mother of child with autism experience more stress than mothers of normal children.

Nicholas Falk in Tasmania in 2012 found that parents of children with autism show high level of stress, anxiety and depression than the parents of developmentally normal children.

Sujata Sethi, Raghu Gandhi, Vidhu Anand in Rohtak in India in 2012 did a study and found that parents of children with ADHD report higher level of stress as compared to parents of normal children.

Narmada Hidangmayum and Pushpa B Khadi in India in 2012 found that parenting stress of mentally challenged children was much higher than that of the normal children.

A study done in Iran in 2013 found that there is significant difference at stress level between parents with mentally retarded children and those with healthy kids.

Blerina Aliaj in Europe in 2013 found that mothers of children with Down Syndrome have higher level of stress, anxiety and depression than mothers of children with typical development.

In 2016 a study was done in Oman where it was found out that the caregivers of children with intellectual disabilities have adverse psychological states that manifest as stress, depression and anxiety than the caregivers of typically developing children.

Sarika Manhas and Kanika Gupta did a study in India in 2016 found that parents of children with disabilities experience higher level of stress than parents of normal children.

Ciara Padden, Jack E. James in 2017 in UK found that parents of children with ASD reported significantly higher level of parental distress, anxiety and depression than parents of typically developing children.

Margarida Pocinho and Liria Fernandes in Portugal in 2018 found that parents with children with disabilities showed higher level of anxiety, depression and stress than the other parents.

Nishant Kumar, Lokesh Kumar Ranjan, Rishi Panday, Manisha Kiran in India in 2018 found that the parents of children with mental retardation have high parenting stress as compared to parents of children with normal controls.

While parenting stress has been studied in many developed countries, few studies have been done in developing countries. Shortage of resources, medication, medical equipment can add to the stress of raising children with disabilities. The purpose of the present study was to assess the level of stress amongst the caregiver of children with and without disability.

METHODOLOGY

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Objective of the study: The basic objective of the study is to indicate that parents of children with disability experience caregiving stress syndrome as compared to parents of children without disabilities.

Hypothesis:

- i. There will be a significant difference amongst the caregiver stress syndrome of special parents as compared to normal parents.
- ii. Level of caregiver stress syndrome of special parents will be significantly higher than the parents of typical children.

Sample:

The participants were parents of children with developmental disability and typically developing children, recruited through normal schools and institutions that support people with disabilities in Gurugram. Total 52 parents agreed to participate in the study. The parents of children ranging between 10-18 years of age were taken as subjects. They belong to different castes, socio-economic classes and educational level, so that a cross sectional sample can be obtained.

Survey Tool

The instrument used was Parenting Stress Scale (PSS) by Berry and Jones 1995 is a short form having 18 items which are self-report measure in which parents respond their typical relationship with their child for which the respondents have the option of choosing strongly disagree, disagree, undecided, agree, strongly agree. To compute the parental stress score, the positive items 1,2,5,6,7,8,17 and 19 are reverse scored, and then, all items are summed. Higher scores reflect more parental stress. The possible range of the PSS is 18(low stress) to 90(high stress).

The scores of the scale were reliable, with a coefficient alpha of .83 and a mean interitem correlation of .23. A 6- week test-retest correlation was .81.

Research tool:

Statistical Analysis: Data was analysed using SPSS software. T ratio were applied to the comparative difference among both the groups.

Result:

Variables	N	Mean	Standard Deviation	Standard Error mean
Stress level of parents of special needs child	26	43.3462	10.60544	2.07990
Stress level of Parents of normal child	26	32.8077	3.32288	.65167

The result shows that the t-ratios are significant at the level of 0.05 and 0.01 both levels.

Discussion and result:

A comparative study was conducted on a sample of 26 parents of special needs and 26 parents of average children. It is a very simple study to prove that there is a fair amount of caregiver stress syndrome amongst the parents of special needs children.

For this purpose, PSS was used for both the groups of parents scoring of the scale was done very judiciously. After collecting the sample data t ratios were applied and the results proved our hypothesis that there is significant difference amongst the stress level of parents of both the groups.

Parents relate their stress with the qualities of the children that make difficult for them to carry out the parenting role.

Similar studies have also revealed that parents of disabled children in comparison to with parents of normal children experience higher levels of negative effects, stress, less social and mental welfare. Parents will never totally accept their child's disability.

Hung *et al.* (2004) a significant difference was observed between different diagnostic groups regarding each stress subscale.

Seltzer *et al* (2001) also found that parents of children with developmental problems in comparison to parents of children with psychological problems had experienced high level of stress.

Among all the observed loads of parenting, parents believe that management of their child's troubling behaviour is the most pressuring challenge. There is also an emotional load related to being ashamed of their child can never experience a normal adolescence and being worried about who is going to take care of their child after death.

As a result, these kinds of chronic pressures on the parents of disabled children experience more higher levels of stress compared with the parents of normal children.

Lazarus and Folkman 1984, suggests that the longer someone spends trying to cope with a stressful condition, the better they would able to adjust with the challenge. During time, parents would adjust with the stress caused by their child's disability, hence they well learn new skills to have better react and responds towards their life conditions.

Limitations of the study:

It was a cross sectional design and sample was too small and we were not able to expediate about the ways to address caregiver stress syndrome.

Because of being occupied with the care of the child our sample could not spare much time to fill in some more variables leading to stress and anxiety amongst the parents.

The result of the study shows that most of the parents in our sample population must be suggested ways and given options to overcome the caregiver stress syndrome.

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