Abstract

Children with disabilities were considered as one of the most important sections in the society who were living in a vulnerable condition. So these types of children need extra care and attention from the family, especially from the caregivers like parents. Caregivers of these disabled children face a lot of difficulties throughout their life. They did not get enough time for themselves also. They lost all the social interactions and also they feel like an out stander in the society. The caregivers also face a lot of stigma from the society. Lack of awareness is the major reason for this. They were experiencing different types of burden while caring their disabled child. The main objective of the study is to understand the prevalence of caregiver burden of children with disabilities. The purposive method is used to collect the data and the researcher used the Zarit Caregiver Burden Scale consist of 22 questions and collected data from the 60 respondents. All the collected data was entered and later analyzed through SPSS. The target group of the study is the parents of disabled children of Vimala Hridaya Special School of Kollam district. From the findings, the study depict that majority of the caregivers are suffering from mild to moderate burden related with the severity of the disability. The study is concluded that the health authorities and other healthcare providers should shift their focus to the mental and physical condition of the caregivers along with the disabled child.
I. INTRODUCTION

Children with disabilities are one of the most vulnerable sections in the society. Families of these children experience a lot of physical, social, emotional, economical and psychosocial problems while dealing with the disabled child. While the most caregivers are mothers and fathers. But now, the grandparents are also come under the parental role. The World Health Organization has defined disability as “any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being”. It is not much easy to give proper care and attention for the disabled children. Some of the caregivers like parents adjust with the problematic behavior of the child and some others do not. For the better adaptation with the child, the caregivers need maximum support and love from the other family members, friends and from the community. While raising a child with disability, the caregivers were all experience heavy stress and depression and also they were face less social support from the society, hence it became burden for them. They also face heavy stress and they feel irritation due to the child’s behavioral problems. The different sources of stress include lack of finance and support, variation in the lifestyle of the family and also the parental conflicts associated with the caring of the disabled child. Parents are also afraid about the safety of their child.

Caregiver is a person who gives help and protection to someone such as a child, an old person or someone who is ill. Most of the parents do not like to admit that they have a disabled child. They keep their child from the front of others, because of the fear of criticism from others. Stigma from the part of the community is a major factor which contributes the level of burden among the caregivers. These types of stigma not only affect the disabled, but also it destroys the whole family. There are a lot of myths and beliefs about disability. The blaming words of the community hurt the caregivers, especially the parents of the disabled children. Parents feel embarrassed or ashamed that their child is disabled. Lack of knowledge is the main reason for this stigma. So it is very essential to educate the community as a whole.

Caregiver burden is defined as “a multidimensional response to physical, psychological, emotional, social and financial stressors usually associated with the experience of caring” (Kasuya, Polgar-Bailey, Takeuchi, 2000). Caregiver stress and burden are mainly focused on the mothers of children with disability, because mothers were the only person whom every child has to depend up on deeply. Mothers meet with more stress and depression than fathers because mothers carry excessive amount of roles and responsibilities for caring their disabled child. The caregivers, especially the mothers did not get enough sleep, fail to eat regular and nutritious food and also failing to get any medical assistance for themselves, if needed. They were also isolated from social activities and they have low quality of life. Caregiving for a child is considered as an additional role for the parents, where the child is disabled and also the caregiver consider the needs of the child as a prime concern and putting their own needs and wishes second place. If a disabled child needs extraordinary level of care from the
Caregivers, they will be forced to leave their jobs or reduce the working hours for meeting the child’s needs. The caregivers also force to spend higher amount of money for medical care, transportation, tutoring, private education, adaptive learning equipment and other health needs for caring the disabled child. Parents may have to save aside money in a trust fund for the care of their child when they pass away. It is more expensive to raise a child with disability than a normal child. So financial burden can be considered as an important factor for the caregiver as a burden.

Most of the caregivers also experience greater amount of depression while caring a child with disability. If the caregiver is depressed, they become blank and they will miss out majority of the social interactions. These less social interactions will lead to poor quality of life. When families experience wide range of stress related to the care giving of the disabled child, it may negatively affects the overall quality of the family life. It is said that disability is a family disease too. Caring for a disabled child brings a lot of challenges to caregivers. The unbearable treatment cost of the disabled child is another important challenge the caregivers were facing through their entire life. The child’s problematic behavior and the social stigma associated with the disability also contribute a lot of challenges for the caregivers of disabled children. Parents of disabled children experience more physical health problems, poorer psychological well-being and psychosocial problems than the parents without a disabled child. The caregivers often fail to pay attention to their own needs such as food, health and other daily routines. So they became unstable to take care of their disabled child. This may greatly affects the care of the disabled child. The child may not get adequate and better assistance from the caregivers.

When parents realized that their child has a disability, they totally depressed and started their journey with the disabled child, which is full of strong emotions and a lot of anxieties. On the initial step, they don’t know how to respond or react to the situation, how to cope up with the condition and not know where to start their search for information, assistance, services, support and understanding. The caregivers may feel isolated and alone, no one give them support and love at that moment. They may miss out many family-related activities and functions, because the child’s disability prevents them from successfully participating. Most of the parents of the disabled children often feel that they are the only responsible person who can handle their child’s care. But it is not true, everyone in the family has the same responsibility for caring the disabled child. To be sustained through the unplanned journey of caring for a child with special needs, it is essential that the caregivers may attend to their own needs. The caregivers may encounter some types of judgments and criticism of their parenting from others who don’t understand their child’s disability. They also may feel guilt over the limits of their ability in providing care and protection for their child. And they may have guilty feelings over the other members of the family for the caring of the child.

Caring a child with disability is a struggle, but it can also be extremely emotionally rewarding. The disabled child needs drain greater amount of energy, time
and money. And also majority of the caregivers are not able to manage the difficult behaviors of their child. They may feel like an outsider around the other parents of normal children. Parents of disabled children suffer increased levels of stress and burden. Challenges with relationship difficulties, financial issues, loss or change of career, family conflicts in opinion with the caring of the child etc. are all causes a great impact on the burden of the caregivers. Anyway caring and protecting a child with disability needs extra emotional strength and strong mind. It is an enormous responsibility; one can far exceed that of a normal child. Parents of children with severe disabilities suffer more burdens while caring their child. They need extra strength and support from the family and from the community. The negative attitudes and criticism of the community also increases the burden of the caregivers and these judgments may worsen the emotional condition of the caregivers. They may easily disappoint and become exhausted by hearing these judgments. This will easily affect the caring of the disabled child. The child may not get adequate care and assistance from the caregivers. So in this present scenario, it is significant to study about the caregiving burden experienced by the caregivers of the children with disability.

II. REVIEW OF LITERATURE

- Ross, Blanc, & McNeil reported that parents of disabled children show more burden in giving care to their disabled child. Child’s caregiving represents an additional role to the family and requires that caregivers consider child’s need as a priority, putting their own need second place.

- Caring for a disabled child may impose direct costs on family for medical care, transportation, parental labour-market activity, and other health care needs. If a child requires exceptional level of care from parent, the parent might reduce hours of work or leave the job to meet the child’s needs. Families caring for disabled children are likely to experience more material hardship and economic insecurity (Meyers, Lukemeyers, & Smeeding).

- Shortage of resources including food, medication, durable medical equipment, and apparel can add to the stress of raising children with disabilities. In condition of poverty, a child with a disability is regarded as a burden, an evil spirit, and an object of charity without rights, rather than as an unfortunate child (Pal & Choudhury, 1998).

- Brown and Bramston, found significantly greater stress in parents of young people with intellectual disability in all aspect of stress examined including stress from the child with disability, internal family stress, from financial strain of having a family member with disability, stress from community etc. (1998).

- Assessment and amelioration of parenting stress is critical to the welfare and quality of life of the child and the family (Brinchman, 1999).

- Younger caregivers experiencing higher stress as they gained higher burden scores because they manage more commitments such as career, family and work compared to the Caregivers age more than 65 years old (Cain and Wicks, 2000).
It is recognized that under some condition, where families have an abundance of social, emotional, and material resources, the stress of caregiving can be minimized. However, the fact that very few real-life families enjoy such positive conditions, it remains overwhelmingly questionable that home care is a positive experience for the family as a whole (Cummins, 2001)

When there was an increase in the age of the child, there will also be an increase in burden. They classified that the increase in age of children including their increase in child’s physical size. The age of caregiver also contribute to be one of the factors influencing the level of burden caregiver of disabled children (Datta, Russell et al. 2002)

Emerson stated that the family having an intellectual disability child tends to economically disadvantaged compared to the family supporting a child that does not have intellectual disability (2003)

There are significant social, physical and emotional burdens associated with the lives of caregivers of seriously disabled children (Mac Donald & Callery, 2007; Wakabayashi & Donato, 2005)

Parents expect to provide caregiving during the growth of a child, the caregiver role takes on a new significance when parents are raising a children with disability, especially since recent practice supports caring for these children in the home (Raina et al., 2005)

Individuals involved in the care of seriously disabled children are at risk of experiencing health problems (Talley & Crews, 2007)

In the past, parents often outlived their seriously disabled children; there is no longer the case. Individuals living with many different kinds of disabilities are living longer and better and this means caregivers are attending to the needs of the disabled for a growing portion of their lives (Mac Donald & Callery, 2007; Talley & Crews, 2007)

Caregiving is a crucial service in societies, often offered without pay, it preserves the health of disabled or aging citizens. State health systems would be unable to provide adequate coverage to the disabled without the caregiver contributions (Talley & Crews, 2007)

Talley and Crews indicated that caregivers require supportive services for their care giving tasks and good health status is needed to provide better care for the needy. Caregivers who are younger may experience a significant protective factor in the care giving to a young child, despite the stresses and adjustments experienced to the family (2007)

Mothers of mentally disabled children have poorer psychological health than mothers of non-disabled children. Shifting the rehabilitation services from child-centered to family-centered services through providing supportive services is recommended (Al-Kuwari, 2007)

Unlike professionals who provide similar care in institutions, parents may not receive regular breaks from care giving. As a result, parents, over time, experience health and social consequences related to care giving. Forms of relief, such as respite care, is one
form of offering a short break from caregiving, and such relief is frequently cited as an unmet need by such parents (MaceDonald & Callery, 2007)

- Caregivers require supportive services for their caregiving tasks, but also supportive services to find quality of life and balance in their lives (Talley & Crews, 2007)

- In some situations, seriously disabled children who move into institutions from living at home often do so not because of a significant change in their health status, but because of the increasingly poor health of the caregivers (MacDonald & Callery, 2007; Talley & Crew, 2007)

- Caregivers learn to deal with burden by using coping mechanisms that lower stress and strain. Some of these mechanisms include support received from social and financial relationships, as well as from health care professionals (Cavallo et al., 2008)

- When a child with disability receives professional health care, the needs of the child are generally the focus rather than on how parents are coping with the situation. Consequently, if the family as a unit is the focus of care and support, caregiver burden can be relieved, especially during those difficult experiences when a child may be hospitalized or receiving therapy (Al-Krenawi et al., 2009)

- Caregivers are often faced with the possibility the child with disability may require long-term care well beyond the typical child raising years, as these parents remain in the caregiver role longer and are continually required to sacrifice their own needs over the child’s needs (Nguyen, 2009)

- In addition to the general challenge and pressure of raising a child with disability, other factors are also linked to caregiver burden. For example, education is associated with the level of psychological stress (Al-Krenawi, Graham, & Gharabeh, 2011)

- Parents also report increased burden when there are few resources available to help them find good healthcare and support for their child (McManus et al., 2011)

- Caregivers with lower level of education tend to have higher self-esteem from care giving which lead them to derive less burden of taking care disabled children (Salama 2012).

III. RESEARCH OBJECTIVES
1. To study about the prevalence of burden of caregivers of children with disability
2. To understand the burden level of parents of special children

IV. THEORETICAL & OPERATIONAL DEFINITIONS

THEORETICAL DEFINITIONS
i.) **Children with disability**: As defined by IDEA, the term "child with a disability" means a child: "with mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and who, by reason thereof, needs special education and related services."
ii.) **Burden**: Zarit, Reever, & Bach-Peterson (1980) define burden as the impact that caregiving has on the primary caregiver, that is, the degree to which the caregiver perceives that the different spheres of his/her life.

iii.) **Caregiver**: someone who provides for the needs of children or of people who are ill or cannot provide for their own needs (American-English dictionary).

iv.) **Caregiver burden**: defined as “a multidimensional response to physical, psychological, emotional, social and financial stressors usually associated with the experience of caring” (Kasuya, Polgar-Bailey, Takeuchi, 2000).

**OPERATIONAL DEFINITIONS**

i.) **Burden**: a duty of responsibility that is hard to bear.

ii.) **Caregiver**: someone who provides for the needs of children or people who are ill.

iii.) **Caregiver burden**: It describes the physical, emotional and financial duty of providing care to the needy.

iv.) **Children with disability**: this means that the child having mental retardation, hearing impairment, a serious emotional disturbance, intellectual disability who require special education and services.

V. **RESEARCH PROCEDURE**

In the present study, it is to investigate the prevalence of burden of parents of disabled children. Hence for this, descriptive research design is adopted. Descriptive research is a study designed to depict the participants in an accurate way. More simply, descriptive research is all about describing people who take part in the study.

i.) **Universe**: Parents of disabled children in Kollam, Kerala

ii.) **Population**: Parents of disabled children in Vimala Hridaya Special School, Kollam

iii.) **Inclusive Criteria**

- Parents of disabled children
- parents who give consent and cooperative

iv.) **Exclusive Criteria**

- parents who didn’t give consent and cooperative
- parents with substance dependence

v.) **Sampling**: Purposive sampling method

vi.) **Sample size**: Sample size of 60 parents of disabled children

vii.) **Tools for data collection**: Zarit care giving burden scale (2000) developed by Park et al is used to assess the burden experienced by the parents of disabled children

viii.) **Statistical method**: Statistical analysis of data is carried with the help of SPSS package

ix.) **Ethical consideration**: We will not force anyone to answer the questionnaire and also make sure that all the personal information of the respondents will be confidential.
VI. DATA INTERPRETATION AND ANALYSIS

Table 1: Respondents Age Group

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid</td>
<td>30-40</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>40-50</td>
<td>24</td>
</tr>
<tr>
<td></td>
<td>50-60</td>
<td>18</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>60</td>
</tr>
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</table>

The age indicates that 30% of the respondents belong to the age between 30-40 and 30% belong to the age between 50-60 and 40% belong to the age between 40-50.

Figure 1: Respondents level of burden
The graphical representation indicates that the female respondents are facing greater level of burden and they are about 60%. The male respondents are only 40%.

Figure 2: Overall Burden

The graphical representation indicates that the female respondents are facing greater level of burden and they are about 60%. The male respondents are only 40%.
The researcher find out the fact that 22 respondents (36.7%) ‘Frequently’ feels overall burden in caring their disabled child and 33% of the respondents ‘sometimes’ feels that they were facing overall burden. About 20% of the respondents ‘rarely’ feel heavy burden and 5 respondents (8.3%) ‘Nearly always’ having the feeling of heavy burden in caring their disabled child. There is only 1 respondent who ‘never’ feel heavy burden in taking care of their child.

<table>
<thead>
<tr>
<th>Level of Burden</th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little or no burden</td>
<td>4</td>
<td>6.7</td>
<td>6.7</td>
<td>6.7</td>
</tr>
<tr>
<td>Mild to moderate burden</td>
<td>31</td>
<td>51.7</td>
<td>51.7</td>
<td>58.3</td>
</tr>
<tr>
<td>Moderate to severe burden</td>
<td>20</td>
<td>33.3</td>
<td>33.3</td>
<td>91.7</td>
</tr>
<tr>
<td>Severe burden</td>
<td>5</td>
<td>8.3</td>
<td>8.3</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>60</td>
<td>100.0</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

As far as the data collected from the 60 respondents, the researcher find out the fact that there are 4 respondents who have ‘little or no burden’ for caring their disabled child and there are 5 respondents who have ‘severe burden’, those who needs special supporting system and supervision. There are 20 respondents who were facing ‘moderate to severe burden’ while caring their special child and also 31 respondents who were suffering from ‘mild to moderate burden’ for caring their disabled child.

![Figure 3: Level of Burden](image-url)
The researchers illustrate the fact that an alarming rate of above 50% of the respondents were facing from ‘mild to moderate burden’ for caring their disabled children. There are about 33.3% of the respondents feels ‘moderate to severe burden’ while caring their children. 8.3% of the respondents were facing from ‘severe burden’, hence they were the target groups and they need special attention and social support. There are respondents who having ‘little or no burden’ comes under below 10%.

VII. FINDINGS & DISCUSSIONS

i.) Majority of the respondents who participated in the study are between the age group 40-50. And also most of them are women caregivers. Every child, includes disabled child depends up on their mother for their daily needs, because mother is the only person who can give maximum care and attention to the child, whether the child is a disabled or not. Caring a disabled child is not an easy task to perform. It is an enormous responsibility, one that can far exceed that of typical parental care.

ii.) With regard to the caregivers, majority of the respondents are always suffering from greater stress due to their child’s illness, because they were greatly isolated from other family members, society and other social activities.

iii.) Results suggested that majority of the caregivers are suffering from mild to moderate burden, this is related with the severity of the disability

iv.) Majority of the caregivers are suffering from all types of burden including financial burden, social problems etc., because most of them were uneducated people and they have low income levels. Lack of knowledge is also an important factor for these burden

v.) Results indicated that the dependency of children towards the caregivers is an important predictor of the caregiver burden

vi.) The caregivers of disabled children may be spending most of their time for care giving and they may not get enough time for themselves for doing any exercise or take care of their health and also they may not get enough time for sleep. This may leads to several health issues and hence they also experience increased levels of stress

vii.) There are 5 respondents (8.3%) who were suffering from severe burden, because they are unable to maintain family relationships, other responsibilities, poor physical health, and disturbance in social life, less privacy concern, higher level of stress, financial difficulties, bad effects on friendship etc. The increased dependency of the child who having severe disability also leads to severe burden to the caregivers.

viii.) Majority of the respondents are always afraid about the future of the child, because the disable children were one of the most vulnerable sections in the society and also they were more prone to sexual abuses and other hazardous situations.

ix.) Medical services offered to the disabled persons should also shift from individual level to family level, especially towards the mother caregivers, because the caregivers were more overburdened and they also needs medical services.

x.) There is a great need for interventions from the government side to take a focus on
the caregiver burden, because they have been ignored. So make necessary family based schemes and programs for the children and caregivers

xi.) Special skilled programs must be provided for the caregivers that helps them to cope with the stress related to the caregiving and they may effectively work with their children and also it improves the quality of life of both the caregivers and the children.

VIII. CONCLUSION

Family is the first support system for the disabled persons in any society. The caregivers of these disabled children experience economic, physical and emotional burden while caring the disabled persons. Their social life also suffered by caring these persons. Family caregivers who look after other family members also need special assistance and attention, otherwise they became totally depressed by the over burden. Hence, self-care is also an important element that every caregiver should take for consider. Caregiver burden is an important outcome that must be understood and also in order to reduce its impact on the families. This type of understanding will helps to get benefit for both the caregivers and the disabled children. Majority of the caregivers were afraid about the future of their child. Awareness about disability among the community and its management system must be build up, because most of the caregivers are mothers. In our country, there are limited resources and it is the best time to realize that we may not develop holistic health of the patient if the caregivers are overburdened. So it is very necessary that the treatment providers and other health authorities should shift their focus to the mental and physical health of the caregivers too along with the persons with disabilities and also it should be helpful in the better caregiving process.

IX. SUGGESTIONS

- The main focus is to make awareness about disability among the community through various actions. It helps to reduce stigma among the people in the community and also it leads to reduce the social burden suffering by the caregivers of disabled children, because most of the caregivers social life and family life has been disturbed by the illness of their child. The reduction in stigma will leads to the overall quality of life of the caregivers.
- It is also insisted that the caregivers must think about their psychosocial conditions and must take considerable care.
- Promote self-care in order to reduce the burden experienced by the caregivers. The better physical condition of the caregiver will be benefit for the proper care and attention for the disabled child.
- Increase knowledge about the welfare measures and rehabilitation measures to the public at regular intervals. This will helps the caregiver to provide better care and greater support to their children.
- Well targeted treatment measures and prevention programmes should be build up.
This paved the way for the better living of the disabled people and also it increases their longevity.

- Skills training programmes to the caregivers can help them to deal effectively with the disabled children which results in improving quality of the life and it helps to take positive steps to handle their children more effectively and constructively.

- Effective assessment of burden at regular intervals and social support is recommended. This helps in counselling the caregivers to reduce their stress and burden which helps to guide their children appropriately. This helps them to accept their children as they are and also they have to show hostility towards their children.

- Ensure that all the policies and programmes for the disabled child should be going properly.

X. BIBLIOGRAPHY


TO CITE THIS PAPER