

**Journal of Science, Technology & Development**

**UGC Care Approved Journal**

UGC CARE LIST - Group II

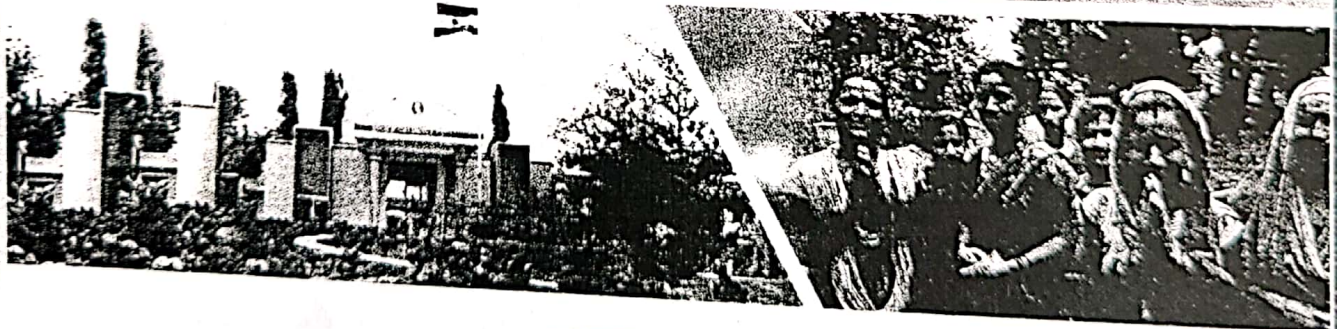
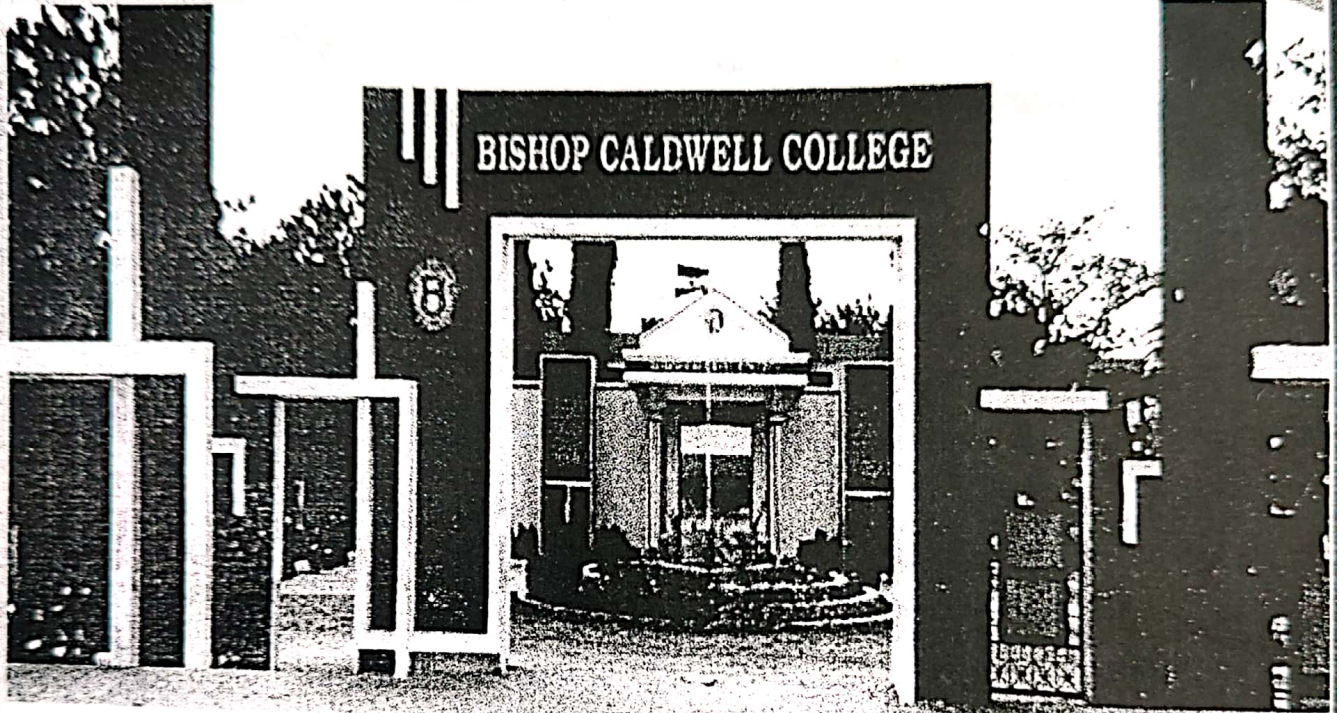
Impact Factor 6.1

ISSN No : 0950-0707

Issue : Volume IX, Issue III, March 2020



**One Day National Seminar  
on  
Marginalization of Women & Dalits  
06<sup>th</sup> March 2020**



**Organized by**

**Department of Sociology  
BISHOP CALDWELL COLLEGE**

*(Affiliated to Manonmaniam Sundaranar University)*

**Maravanmadam, Tuticorin - 628 101**



## **A Study on the Psycho-Social Problems and Coping Strategies of Parent-Caregivers of Visually Impaired Children**

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### **Abstract**

For many parents, more so in developing countries, having a child with a disability involves dealing with multiple emotions like guilt, blame, or reduced self-esteem as well as disappointment, sadness and depression. Among caregivers of children with visual impairment, the burden of routine care giving is manifold as the children with impaired vision need help with everyday activities, treatment, finances, and emotional support. This paper is based on a study of psycho-social problems and the coping strategies of the caregivers of the visually impaired children. Adopting qualitative approach, the study compared the experiences of two-groups of parent-caregivers of children with visual impairment – caregivers of children who were visually challenged by birth and caregivers of children who had lost vision subsequently (after having normal sight at the time of birth). Using focus group discussion, data were collected from the caregivers of visually impaired children associated with a leading School for the Visually Impaired in Chennai. The study gave insights into the psycho-social problems and the coping strategies of the caregivers of the visually impaired children. It has helped to understand the challenges they faced, the support system and their expectations on the society.

**Key words:** Disability Issues, Visual Impairment, Caregivers, Psycho-social problems, Coping strategies, Qualitative Study

## Introduction& Statement of the Problem

Disability is not only concerned with an individual alone, but has an impact on the entire family and the support network. Expecting parents normally wait for a healthy child and have great dreams for the child. Once they come to know that their child is born with disability, they are shattered with strong emotions. Parents suffer from mental stress all the more when they come to know that their child has visual impairment. Initially the parents refuse to accept and deny the problem, but then they begin to come along and accept the visually challenged. Children with impaired vision need to be helped in assisting with their everyday activities, social learning, finances, and emotional support which may manifest as the burden of care giving. This may result in psycho-social problems for the caregivers themselves, more so for the parent-caregivers. This study aims at understanding the problems faced by the parent caregivers of children born with visual impairment or of children that became visually challenged later, and the coping strategies adopted by such parent caregivers.

## Significance of the study

Giving care to the children with special needs is a lifelong commitment. Care giving plays an important role in the life and growth of the visually challenged children. Hence a study among parent caregivers become pertinent. Further, understanding the psycho-social issues faced by the parent caregivers and coping strategies is important not only to identify behaviours that are worth emulating but also to identify gaps that need to be addressed.

## Review of Literature

### Definition of Visual Impairment

According to the report of the World Health Organization (WHO, 2019)“Blindness” is **defined** as a presenting visual acuity of worse than 3/60 or a corresponding visual field loss to less than 10° in the better eye. “Severe visual impairment” is **defined** as a presenting visual acuity of worse than 6/60 and equal to or better than 3/60.

### Definition of Caregivers

According to the Cambridge dictionary, a caregiver is defined as “someone who provides for the needs of children or of people who are ill or cannot provide for their own needs”. Caregivers could be formal or informal. Formal caregivers are paid for the care they provide.



Informal caregivers are the ones who provides ongoing assistance for the disabled or elderly patients without any payment. Roth et al. (2015) defined the informal caregivers as individuals assisting the disabled persons with activities of daily living. In this paper, the term 'parent-caregiver' is used to refer to parents who serve as informal caregivers and not other persons.

### Experiences of Caregivers

Murphy et al (2007) reported that meeting the day-to-day requirements of the children with disability caused emotional and psychological stress among the caregivers. They found that the caregivers experienced difficulty in performing their daily activities due to physical pain because they provide the direct and daily care for the children with disability. It was found that the caregivers of the children with disability used taking 10-15 min breaks from their heavy responsibilities, mini naps or just cry, enjoyment with pets, doing shopping as coping strategies.

Eisenberg et al. (1997) stated that the children with disability need to be established with social and emotional skills. The caregivers have to help them because they are not able to be related with their peers and others due to their disability which results in deprivations.

Lupon et al (2018) in their study on quality of life among parents of children with visual impairment by reviewing the existing review of literature reported that the parents need better information and guidance on the diagnosis of the defects of the children. They need to become aware of the services available and receive support on how to manage and get adjusted to the situation.

Dhaliwal, et al (2016) in their study on the "Burden and depression in primary caregivers of persons with visual impairment" found that the primary caregivers of the visually impaired experienced burden and depression as they have to be fully occupied in giving care for the children. The parent caregivers seldom care for themselves.

Bambara et al (2009) reported in their study findings that the caregivers who had a more negative problem orientation were more likely to report more depressive symptoms and less satisfaction with life than were those who reported a more positive approach to managing problems in daily living.

Reichman, et al (2008) in their study found that parents suffer from guilt, blame, reduced self-esteem as well as disappointment, sadness and depression when they have children with disabled children. Troster (2001), in the study mentioned that rearing a visually impaired child heightens the level of stress in the caregivers.

Murphy, et al(2006) in their study finding revealed that the caregivers of children with disabilities expressed negative physical, emotional and functional health consequences of long-term and informal caring. This makes the impact in the parents to have the decreased psychosocial energy.

Warren (1994) reported that visually challenged children are faced with many hurdles in the area of their development as well as in their adaptive functioning. Children need to know the physical world, expand their perception and cognitive skills. These kinds of developmental issues become more stressful for the visually impaired children as well as for primary caregivers.

### **Aim**

To study the Psycho-social problems of the parent-caregivers of the visually impaired children and their coping strategies.

### **Objectives**

- To study the problems faced by the parent-caregivers of the visually impaired children
- To study the coping strategies of the parent-caregivers

### **Research Methodology**

The aim of this paper was to study the psycho-social problems of the parent caregivers of the visually challenged and their coping strategies. A qualitative study was conducted in order to achieve this goal. The field of study was one of the leading schools for special children (visually challenged and hearing impaired) in Chennai. Data were collected from parent-caregivers through Focus Group Discussion (FGD). Two FGDs were conducted during February 2020 among the parent-caregivers of the visually challenged children born with visual impairment and of visually challenged children who became visually challenged later. FGD guide that consisted of 8 open-ended questions with probes was used on parent caregivers of the visually impaired children for data collection. Homogeneity of participants in terms of same age group of children was maintained. Group I (N=8) had mothers of



children who were born with visual impairment and Group II (N=9) had mothers of children who became visually challenged later. The participants were welcomed initially and provided with refreshments. Then the moderator introduced the aims of the FGD and got permission to use audio-recording. The questions were asked from general to more specific. The participants shared spontaneously on the questions on their psychological problems and the responses, social problems and the responses, coping strategies they adopted. The moderator finally summed up the key points that were collected for more insights from the participants. The data were analysed thematically. With respect to study limitations, since the study adopts qualitative approach, the findings are not generalisable.

## Results

### *Profile of the participants*

The participants were in the age group of 25-45 years. Majority of the parent caregivers had primary education. A few of them were with high school education. Two were graduates. Majority of the participants were home makers. Three of them were engaged in house-keeping work as part-timers. Most of the parent caregivers come to school along with their children to assist them and fetch them home.

### *Psycho-social Problems*

#### **Shock**

Majority of the participants experienced shock as their first responses to their visually challenged child.

*My child was born without the balls. It was a shock for me to realise that my child was a visually challenged child. My husband and I were not able to accept.*

Participant 1(33Yrs), Age of the child: 9 Yrs

#### **Frustration**

There was also the feeling of frustration experienced by some of the participants. It is natural to have the feeling of shock and frustrations. Though it was difficult in the beginning, the

parents have accepted the reality gradually. The siblings of the visually challenged children extend their care and support to the special children.

*Why God has given us such a child without vision, why only to our family*

*Participant D (35yrs), Age of the child: 9 Yrs*

### **Denial – Gradual acceptance**

The parents were able to accept the child in spite of the mental agony. They love their children though the child is found to be with some form of disability. In some cases, the denial was from the in-laws. They blame the woman for the cause of blindness.

*My in-laws did not accept it. They wanted the child to be killed. But my husband and I moved away to the city in order to save the child*

*Participant E (33 Yrs), Age of the child: 11 Yrs*

*Our child had vision, but later we identified that she had only sided vision. I took her to several hospitals to give treatment, so that my child would have full vision.*

*Participant C (39 Yrs), Age of the child: 10 Yrs*

### **Guilt**

Another participant said that she was not aware of the special schools being in the city. That would have contributed to her daughter's learning of braille. She was guilty of bringing her children late to school education

*I have not put the child in a special school earlier which would have made the learning easier for my daughter. I sent her to the sighted school first; she is unable to learn the braille*

*Participant F (34Yrs), Age of the child: 13 Yrs*

### **Stress**

As Remier et al (1998) described the burden of caregiving as involving of heavy responsibility, constant worries and constraints in their social life, it becomes a constant challenge for the parent caregivers to give care for the special children. It adds to the burden



of the mother when she has a drunkard husband. She experiences certain kind of stress every day

*My husband is a drunkard, he fights with me. My two sons would run away when he beats me. But my daughter born with visual impairment cannot run and save herself. Whatever might be the struggle, I would keep my daughter with me and care for her. I do the part time job to meet the financial burden*

Participant 7 (34 Yrs), Age of the child: 13 Yrs

### Helplessness

There is also kind of helplessness experienced by the caregivers. When both the parents have no education, it becomes difficult for them to teach their children at home. The following was expressed by one of the participants.

*I do housekeeping job. Since I am not educated, it is difficult for me to help my daughter do the homework. I feel sad and helpless.*

Participant E(33 Yrs), Age of the child: 11 Yrs

The parents cannot be trained in learning the braille method and mathematics to teach their visually challenged children if they have no basic education. This leads to feeling of helplessness among the caregivers.

### Social problems

During the focus group discussion, the participants shared about the social problems they usually come across in having a visually impaired child.

#### ➤ Non-acceptance

A few of them said that they were feeling embarrassed when taking their visually impaired child for any functions. They expressed their unhappiness when their relatives look at them differently. The parents feel that there is non-acceptance of such kind of children. This makes the parents to move away from there fast.

*When I take my child for marriage or any functions, the relatives look at her differently. Still my in-laws and some of the relatives have not accepted. I would feel embarrassed those moments.*

Participants 3 (31 Yrs), Age of the child : 13 Yrs



### ➤ Reaction of outsiders

All the participants said that they were not happy about the reaction of the public. They look at the children as though they were from another world.

*When we bring the children to school by bus, the way the public look at the visually challenged children would make us to get angry. They too much pity the special children. They do not see them as they do with non-disabled children*

Participant 5 (Yrs), Age of the child: 11 Yrs

Majority of them did not want their children to be looked down upon and pitied too much. They gave their reasons that their children are as equal as the sighted children in performing well in their study. Some of them said that their children are equally talented in many ways. The reaction from the outsiders make them unhappy.

### ➤ Isolation

The participants had a feeling that they live a life of isolation. Whenever they move out of their house, they cannot stay longer outside. They were impelled to return immediately to attend to their children's need.

*Two of my daughters are visually challenged. So I do not go out freely and be out of my house. I do not feel to go anywhere leaving my children. They are well cared for by their grandparents, but still I am hesitant to move outstations.*

Participant 4 (39 Yrs), Age of the child: 15 Yrs

It shows that they social life is curtailed. Their social relationships is limited. There is no interactions with the relatives and friends. Their time relaxation is less. They tend to live in isolation.

### Supportive groups

The participants experienced the strength of the supportive groups after coming to the special school. Their confidence in life and in caring for the visually challenged has increased by seeing the parents with similar problems. This has motivated the parent caregivers to provide the best for their children. They would go any heights to educate their children. They were

happy for the school, the teachers who encourage them. This has become the source of consolation and an inspiration to learn from one another in the School. They said that the parent caregivers are given training in learning the braille and the mathematical calculations. They have gained the courage to look at positively about the life of their children. It has become the place of hope.

The study also found that the parent care givers forget their worries and burden as they have the chance to be with other parents who come to the school every day. This becomes the channel of let out for them as they interact with each other. So it is understood that the peer group support plays an important role in releasing the stress of the parent caregivers as others too are of having the same children.

### Discussion

The study was focused on parent care givers of the visually impaired children. It was to understand the psycho social problems faced by them and their coping strategies. The findings of the focus group discussion revealed that the caregivers do face problems psychologically such as shock, frustrations, stress, guilt and helplessness. The results of the two focus group discussions revealed that majority of the findings were similar for the two groups - the responses of both the groups were almost similar except for non-acceptance of the impairment on the part of the caregivers of the children who lost their vision later stage. Also, understandably, the parents undergo a cycle of grief when they know that their child is visually impaired.

Murphy et al (2007) observed that many caregivers do experience burn-out occasionally. It was also found through this study that the parent caregivers experienced the burden of the entire family along with the stress in providing care. The parent care givers reported that they did not have time to care for other children in the family since they had to pay their full attention to the special children. They also reported that their full time is spent in the school and they reach home late. Since they had to be busy in the family chores, they were unable to help the children in their project work. They said that all the project works are done only by the sighted parents. It was not a learning for the visually challenged children. So the curriculum need to be framed according to the differently abled children. They also said that they were unable to complete the tasks at home in mornings since the school starts early. So naturally they experienced a kind of stress and burn-out.



Elliot and Pezent (2008) said that the care givers in depression might show harmful behaviours towards the care recipients. This was not proved in case of the parent caregivers of the visually impaired children instead they show more affection and concern towards their children. Their only aim has become that their children get good education unlike them for which they would go to any extent to provide education. The same authors also stated that informal care is the effective and efficient way of caring for people with disabilities. However it would have its significant consequences on the health-related issues of the caregivers. The parent caregivers were found to be with the children all the time. This has lead them to unemployed. The world report on disability (2011) stated that the time-consuming responsibility of giving care to the persons with disability might reduce the employment or giving up the employment leading to financial challenges. This is true in case of the parent care givers who have no employment due to their commitment of being in the school full time.

From the findings of the focus group discussion, it was identified that the parent caregivers had experienced social problems such as non-acceptance of the disability from the family as well as from the society. From the study of the Oraibi et al (2011), it is proved that caregivers experience a very little or no support and are not prepared for their role to provide care which could lead to burn-out and stress. From this study also, it became clear that the mothers of the visually challenged children did not get the support of the family. The whole burden of the family falls on the one who gives care.

The reaction of the public hurt the parent caregivers of the visually challenged whenever they see the children. So it is the role of the media to bring awareness to the public about the children with disability and to train them to respect their individuality.

Gull and Nazami (2015) indicated in their study that the parents might suppress their vision about their children upon discovering the child with some disability. In this study, it is understood that the parent caregivers have some aspirations and dreams for their children as they might experience different emotions. The parent caregivers expressed that they would not think of getting their daughters in marriage where as they would like to settle them with good job. As long as they are alive, they would care for their daughters. They would leave it to the hands of God once they were gone.

### Suggestions and Scope for further research

The study showed that the parent caregivers experienced the psychological problems such as shock, frustrations, stress, helplessness, grief and guilt when they realized that their child had visual impairment. There could be supportive groups where they would feel free to ventilate and express their emotions. The supportive groups also helps to solving their problems. The parent caregivers also face social problems such as isolation, reaction of the outsiders and non-acceptance from the society. Since the parent caregivers who have minimum educational background find it difficult to do project work which is mandatory for the visually challenged children, it would be better if the curriculum is designed for them separately. There could be an establishment of a counseling centre for the parent caregivers as well as for the children.

This study is qualitative in nature. But a study with quantitative method could be conducted in order to find the problems in a larger group both for the homogenous group of men and women.

### Conclusion

This study reveals that the parent caregivers do face the psycho-social problems. But the supportive networks among them provide space for ventilating their emotions of grief and other problems mentioned in the study. Their interactions with the Institution where the visually challenged children and their abilities are respected become the source of strength and hope. The parent caregivers feel happy experiencing that their children are enlightened, have become active and courageous. The coping strategies that they follow were the acceptance of the child, showing more affection and love towards them, spending their time in school with other parents. They made a special mention that they did not want to have inclusive education for which the infrastructure need to be equipped and the trained personnel to be appointed for effective learning. They forget about their problems as they come to school every day accompanying their child. This leads to financial crisis in the family.