

The Challenges faced by Primary Care Givers of Children with Intellectual Disability

Aneesh Joseph¹, Dr. Anita Machado²

^{1,2}IGNOU, Kottayam, Kerala

Abstract- The primary caregivers in this study understood as the parents in relation to the care of children with Intellectual Disability. Their challenges vary from different aspects like health, psychological, relational, social and economic. The researcher found that most of the respondents of the study felt a mild to moderate burden on caring their children with intellectual disability. Along with their other responsibilities and duties of their family they were compatible in caring their children with intellectual disability. This study used descriptive research design with a mixed methodology based on quantitative and qualitative data. Convenience sampling technique followed for data collection. There were 58 parents as respondents of the study and they were selected from two NGOs in Satara, Maharashtra. This study conducted in 2014. The challenges of Primary Care Givers were measured using caregiver distress scale and zarit burden scale. The study also looks at the interventions of special schools in the developmental process of children with intellectual disability and the usefulness of these interventions in coping with caregivers' burden and distress. The study found that the respondents' feel a moderate burden in caring their intellectually disabled children. The economic burden is higher than other factors because the majority of the respondents were from a poor or average income generated families. The intervention of special school education helped them to tackle the challenges. The study also found that care givers are mostly having a positive look on disability.

Key words: Primary Care Givers, Children with Intellectual Disability, Care Giver Burden, Care Giver Distress, Functional Level, Special Education, Special School

1.INTRODUCTION

Disability is a multi-dimensional and complex construct and its definitions differ across countries and even within the country with evolving legal, political and social discourses. Data collected from 147 countries presents as: mental retardation (most common term in 76% of the countries), intellectual disability (57%), mental handicap/ disability (40%).

Other terms like learning/developmental disability and mental deficiency/sub normality are also used (World Health Organization, 2007). Intellectual disability (ID) - mental retardation, which was in use world over till late 20th century, has now been replaced with ID in most English-speaking countries. Diagnostic and Statistical Manual 5th Revision (DSM-V) has replaced it with ID (Chavan & Abhijit, 2014). World Health Organization estimates that 10% of the world's population has some form of disability. Mental retardation (MR) is one form of disability and affects 1-3% of human population (World Health Organization, 2007).

A person with intellectual disability classified from mild to profound and they have limitations in at least two areas. IQ (intelligence quotient) is measured by an IQ test (Webmd, 2015). A person is considered intellectually disabled if he or she has an IQ between 69 to 71 (S.Baroff & Olley, 1999). The key criteria for defining intellectual disability include: significant impairment in intellectual functioning; difficulties in adaptive behavior; and manifestation in the developmental period (Luckasson R, 1992). So, the children with intellectually disability need assistance and care from a care giver. The researcher was trying to study the challenges that primary care givers carried out in their life to bring up their children with intellectual disability. So the purpose of this study was to examine the challenges faced by families with their intellectually disabled children. The main objectives envisaged for this research study was: to study the care givers demographic profile; to examine the distress encountered by care givers; to study the family burden experienced by the Primary Care givers with their intellectually disabled children; to understand the perception of Primary Care givers on Special education; to understand the perceived impact of special education on Intellectually Disabled (ID) children.

2. REVIEW OF RELATED RESEARCH

There are numerous research studies related to the topic of care giving to the intellectually disabled children. The following section will explain different challenges and issues related to care giving of intellectually disabled with the reference of research studies. The families face a number of challenges with their intellectually disabled children. In particular, there is evidence of an increased risk of a host of problems in other family members, including siblings and parents, with this risk being reflective of the broader autism phenotype. The challenges they counter in the family as primary care givers can be summarized into the following points.

1.1. Time Constraints

Time constraints as a challenge is common disadvantage that the parents with disabled children have less time available to their non affected children. Often this was attributed to the heavy demands of the affected child or the need for additional supervision. Parents highlighted the impact on personal time for the siblings themselves because of the burden of helping with care or entertaining the sibling with the disabled one (S.Mulroy, L.Robertson, K.Aiberti, H.Leonard, & C.Bower, 2008).

2.2 Impaired Socialization

Families impaired family socialization, particularly families in the “Missed out on typical family experiences on a regular basis i.e. outings, spontaneous outings”. Taking a family holiday was noted to be very difficult for families of girls with disability (S.Mulroy, L.Robertson, K.Aiberti, H.Leonard, & C.Bower, 2008).

2.3. Routine/Restriction

The necessity of adhering to a regimented routine was frequently highlighted as a disadvantage by parents of having children with intellectual disability. Some Down syndrome families described extra ‘rules’ imposed on the other children such as ‘Keeping doors locked, small toys away, bedroom doors closed.’ in order to deal with the behavioral challenges of the child with Down syndrome. It limits the spontaneity of the family and that leads to sadness and frustration ‘Not as much freedom to get up and do what we want

as a family, spontaneous’ (S.Mulroy, L.Robertson, K.Aiberti, H.Leonard, & C.Bower, 2008).

2.4. Financial Burden

Families of children whose disability was diagnosed early (which would include most children with a genetic or hereditary disability) have been shown to face a greater degree of financial. Similarly, families of children with a severe level of disability face greater economic hardship, as do those whose children’s disability is long-term. Costs have also been shown to increase as the child grows older with increasingly complex health issues (Mollenhauer, King, Bodiam, & Bellamy, 2013).

2.5. Sibling Relationship

There are a number of factors which can impact the sibling relationship with a child with a disability. These include: family structure, gender of the sibling without disability, gender of the sibling with a disability, severity of disability, level of functional capacity, presence of an autism spectrum disorder, presence of challenging behaviors in the child with a disability and well being of the parents. Siblings in other studies have reported a variety of negative emotions felt towards their brothers or sisters with a disability. Some of these emotions include anxiety, embarrassment, bitterness and fear, guilt and shame, deep hurt, loneliness and anger (Mollenhauer, King, Bodiam, & Bellamy, 2013).

3. METHODOLOGY AND RESEARCH DESIGN

The study design was descriptive since the following areas were examined and explained. The study had described the primary care givers challenges in the form of distress, family burden and positive elements in care giving and positive impact of special education in coping with the challenges. This study interviewed the primary caregivers of children who were below the IQ of 70 who were called children with intellectual disability. The sample size for the current study was restricted to 58 respondents. The respondents were selected through convenience non probability sampling method. The criterion for inclusion and exclusion was the registration of their intellectually disabled children in special school studies in both the NGOs.

The primary data for the study was collected through a semi-structured interview schedule administered through personal interview with the primary caregivers of intellectually disabled children and there were some open ended questions too. The researcher used Care giving Distress scale by Parkinson Foundation and Zarit Caregiver Burden Scale. Both of them are standardized scales. It was freely available in the internet and so it is downloaded and used in this study. The researcher got prior permission from the NGOs to interview their school children’s parents. The interview schedule was translated into Marathi except the profile and care giving dimension part because these parts were contained more objective. The researcher also received suggestions from field experts.

4. DISCUSSION

The main domains of the study were demographic profile, caregivers’ distress, caregivers’ burden, functional level of the care recipient and positive impact of the special school intervention. The study found that the respondents’ feel a moderate burden in caring their intellectually disabled children. The economic burden is higher than other factors because the majority of the respondents were from a poor or average income generated families. The purpose of this study was to examine the challenges of primary caregivers in caring their intellectually disabled children. Mostly the primary caregivers in the family circle constitute parents and they face challenges in the form of physical, mental, social and economic.

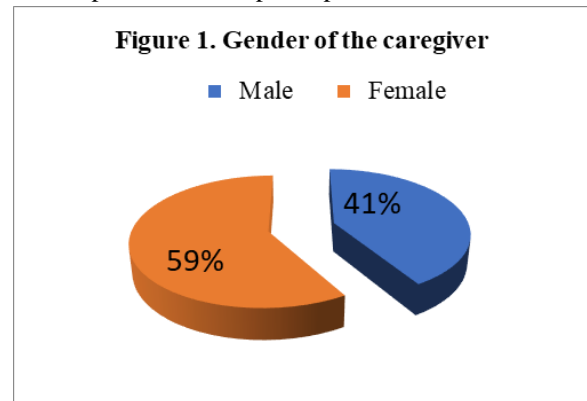
4.1. 1 Demographic Profile

Table 1. Age of the Caregiver

| | Age | Frequency | Percent |
|--|-----------|-----------|---------|
| | 1 (25-35) | 8 | 13.8 |
| | 2 (36-45) | 26 | 44.8 |
| | 3 (46-55) | 17 | 29.4 |
| | 4 (56-65) | 5 | 8.6 |
| | 5 (66-75) | 2 | 3.4 |
| | Total | 58 | 100.0 |

4.1.2. Gender, caste and occupation of the caregiver
 Respondents for the study were both men and women even though the majority were women. The Men are also playing a significant role of care givers along with

Demographic questions were related to the caregiver’s age, gender, marital status, length of relationship with the care recipient, work status, education, marital status, income and occupation. The study had bisex coverage of both male and female respondents. From Figure 1 a safe inference can be drawn that female respondents were significantly higher than the male respondents’ constituting 59 percent male participants and 41 percent female participants.



Most of the female participants of the study were not engaged in any occupation and this could be attributed for the higher percentage of women in care giving than men. The study indicates that even though women are higher in frequency men also played a significant role in care giving.

Enquiry directed into the age of the respondents revealed that majority of the participants were within the age between 36 to 45 constituting 44.8 percent followed by respondents within the age group of 46 to 55 constituting 29.4 percent. The study also observed that there were care givers within the age group of 66 to 75 constituting 3.4 percent.

women. The current study shows a statistical association between occupation and gender ($p = .000$). The respondents who were not in job constituted twenty two and all of them were women. It also

implies that caring task is associated with the role of the mother. Women care givers might have perceived difficulty to go for an occupation besides the caring of the child. A patriarchal thought pattern and gender wise role differentiation is still prevalent and active in India and across the world. Here the caring task is generally attributed to women and the study also shows a similar response in certain extent.

4.1.3. Gender prevalence of Intellectual Disability

National Sample Survey Organization study reports that prevalence rate of mentally retarded was higher among males as compared to females (NSS, 2003). The current study also shows a similar pattern even though it is a small study in its size of respondents. The male children who are care receiver were 70.69 percent and female only 29.31 percent. The reason behind this difference is that the number of male children in the special school was higher than the number of female children in the special school from where the researcher collected the data. It indicates the male dominance of intellectual disability than female.

4.1.4. Age as a factor of burden

The average age of caregiver is 45 and care recipient is 17. Most of the caregivers are in their middle ages and recipients are in their teenage or adolescence. Majority of the caregivers belong to their adulthood and care recipient belong to teenage or adolescence. Grant and Whitell (2000) reported an increase in the use of cognitive coping strategies as parents aged. The majority of the caregivers of current study were in their middle ages and recipients were in adolescence. If the age gap between care giver and care recipient are higher, then the burden for caregiver will be high.

4.1.5. Primary caregivers

According to Cuskelly (2006) a large majority of primary care givers of adults with an intellectual disability were mothers, even when both parents are retired (Cuskelly, 2006). The current study also presents the fact that parents are playing the vital role of primary caregivers. Almost 55.2 percent the Primary care Givers were mothers and 39.7 percent the fathers play the role of primary care giving. So the primary caregivers are ultimately the parents who really take the challenge to nurture these children with intellectual disability.

4.1.6. Education: a challenge before occupation

Majority of the participants of the study have completed school education (N=33) and there was one respondent who didn't have even school education. Their occupation was also mostly connected to their educational status. The study showed that majority were engaged in self-employed occupation in the form of manual labor, driving, farming, running shops etc. Three were only four respondents who were working in government sector.

4.1.7. Income and financial burden

The current study shows that majority of the respondents' income was within the range of Rs.3000 to 5000 constituting 43.1 percent. There was a significant correlation between their income and financial burden. The majority who had less income were feeling extreme and severe financial burden. This is also evident in the current study since financial burden was also coupled with other issues such as Children's educational needs, health issues confronted by other family members and the care recipient had a significant impact on the Finances. Since majority of the household had single earning member it further aggravated the burden.

4.2. Functional level of the care recipient

Functional level of the care recipient is assessed with three domains self-care, mobility, and social function (NDA, 2012). In the present study it was observed that majority of the children were able to take care of him/her except in the area of incontinence in self care; 94.8 percent were able to move by themselves and the majority required help in social function. However, the Research study observed that though 74.1 percent had toilet training, 39.7 percent expressed incontinence due to their physical disability.

4.3. Care giving distress

The study looked at care giving distress with the domains of distress under four domains: impact on relationships (4 items), impact on social life (3 items), emotional burden (4 items), care-receiver demands (3 items) and personal consequences (3 items) (Cousinsa & et.al, 2014). There is a strong positive correlation between impact on relationship and emotional burden ($r = .724$) and it is significant ($P = .000 < .05$) where as the correlation between impact on relationship and care receiver's demand had a weak correlation (r

=.257) and not significant ($P = .051 > .05$). It indicates that respondents feel more distress on relationship, emotion and care receiver's demand compared to social life and personal consequences. *Task-specific theory* emphasizes that most people have various needs, and it is necessary for both formal groups and primary/informal groups to cooperate in most areas of life (Cho, 2007). The disability of the child was not affecting their personal life and social life because of the cooperation and collaboration of supportive systems.

4.4. Caregiver burden

The current study found that among five domains in the scale majority of the respondents feel burden on health, financial, relationship, psychological and social respectively. The mean value was high accordingly on the score. There was a positive moderate correlation between health burden and psychological ($r = .642$), financial ($r = .530$) and relationship burdens ($r = .480$) and this relationship was statistically significant ($P = .000$). These were three areas where majority feels burden on their caring. The respondents didn't feel much social burden in caring their ID child. The distress scale also proved the same finding. There is no explanation for how social support directly affects the physiological processes or physical health (Cho, 2007).

The study revealed that majority of the respondents (53.4 %) feel mild to moderate burden in caring their ID child scored in between 21 to 40. The study found that majority feel that their health was affected mildly (35%) in caring their ID child and respondents who were feeling extreme burden were only 9 percent. The respondents who feel mild psychological burden expressed that their burden was mostly on issues related to privacy. The study found that majority of the respondents feel severe financial burden and it was the only domain where the respondents feel severe burden with high score. The income of the respondents was a major factor that influenced financial burden. The respondents who feel extremely burdened were mostly concerned about the future of their ID child. For the present study, generally, the domain correlations and internal consistencies were higher for health, psychological, financial and relationship burdens. For these domains correlations remained consistent across combinations of time and diagnosis. However, for

social domain there were serious discrepancies across combinations.

4.5. The positive dimension of care giving

Most of the parents reported that accompanying a child with a disability on the road to life became a positive and strengthening experience for them. Findings also supported the recent research that having a child with disability contributed to personal and spiritual growth, family stability, and personal hopefulness (Kausar, Jevne, & Sobsey, 2003). The current study also goes in line with these finding. The current study found that the social life of the care giver is not much affected because of their relationship with their ID child. The study revealed that participation of the respondents in social organized activities is not affected because of their caring task. It indicates that they are having good social net works and it helps to reduce their burden.

4.6. Relevance of Special education for intellectually disabled children

Special education is the education of students with special needs in a way that address the students' individual difference and needs. A special education program should be customized to address each individual student's unique needs. Students with special needs are addressed to determine their specific strength and weakness (Deshprabhu, 2010). The current study revealed that the programs and training offered by both schools produced a positive impact on care recipients and it helped care giver to cope up with care giving dimensions.

5. SUGGESTIONS AND RECOMMENDATIONS

Researcher would like to present the following suggestions and recommendations based on the insights gained from above research study. These suggestions and recommendations are inferred from the major concerns that evolved from the Research study.

5.1 Levels of Intervention

There are three levels of practice: micro, mezzo and macro. Micro refers to practice with the child in the family context. This would include assessments, therapy, brokerage and advocacy for services specific to that child and family. This is often referred to as clinical practice. A mezzo level of practice includes assessment and intervention at a community level,

such as developing fast track programs, responsible childcare programs, respite care for families, public education, and prevention programs. This is often referred to as community practice. The third is macro level, which refers to assessment and intervention at a societal level including legislation and policy making. From the point of view that care giver as service providers, the micro level is the front line worker or provider of service. The mezzo level is management and the macro level is administration and policy and procedures that guide practice.

5.1.1 Micro level intervention

Families typically are the care providers of children with intellectual disability. Parents play mostly the role of Primary Care givers. So the grass root intervention should happen at family level.

1. *Pre marital education*: provide them knowledge about the prevalent nature of this disability and different causes of this disability.
 - A) *Prior intervention*: In early intervention, the child's risk has been identified but symptoms have not yet affected functioning. The primary goal is to identify and address concerns early in the child's life to prevent further progression of symptoms, to provide support and to teach strategies to cope.
 - B) If the parents noticed any developmental delays at the age of 6 or 7, assess the IQ test and start intervention with therapy and special education.
 - C) Ultimately the prior intervention comes from parents. How they look at the disability and their care giving task makes the diffidence. It points out to a *shift from medical perspective to a strength based approach*. Look at their ability than their disability. The children could develop in many areas only because of the prior intervention and constant supervision of primary caregivers and education facilitators.
2. *Promote leisure time and social interactions* for both care giver and care recipient: It is important to reduce the stress of the life. As majority of the respondents of the current study mentioned, their social life less affected by the presence of their child with intellectual disability. Social interactions will help to reduce caregivers' psychological and emotional burdens.
3. *Promote special education*: The study found that school made a positive impact on the functional

level (27%) behavioural level (34%) communication (9%) social interaction (15%) and learning (15%).

4. *Collective responsibility of the family*: PCG share the duty of care giving with other members of the family and try to develop a collective responsibility than overtaxed with responsibilities. The respondents of the study were both male and female and it also indicates a familial collective responsibility that reduces burden.
5. *Family inclusion to develop social skills*: Develop social skills of children with intellectually disability through social interaction and inclusive attitude in family affairs like marriage, visits relatives and friends etc.

5.1.2 Mezzo level intervention

The intervention from school and society come under this level.

1. *Behavioural and functional capacity building of the child*: Majority of the respondents of current study expressed that special education impacted more on behavioural modification and functional level than academic learning. So the school curriculum should concentrate on these aspects. Majority of the respondents also expressed that effective teaching and learning practices were positive dimensions in special education program.
2. *Therapeutic intervention*: Provide speech therapy, physio-therapy and play therapy to deal with the constraints that child with intellectual disability faces.
3. *Technological assistance, training and promotion*: The study found that 43.1 percent of care recipient were able to operate some functions of the mobile. School can introduce and give training to use technological advancement which is adaptive to them.
4. *Transportation*: Transportation was a significant factor that regularized the attendance of the children in school. Regularize school bus facility to increase the percentage of attendance of the child in school.
5. *Supportive group*: At mezzo level the school can formulate a caregiver's support group where they can share their concerns and experiences and each can learn coping strategies from another member of the group.

6. *Training programs:* school organize training program for the care givers. The study found that around 90 percent of them had not attended any training program and around 35 percent of them wish to attend training programs.
7. *Financial assistance through connecting supportive systems and government policies:* the schools can help care givers by connecting them to some NGO who financially support because the majority of the study were from poor financial background or were not able to do a productive income earning job.

5.1.3 Macro level

The states' intervention comes under this level

The state has a responsibility over its citizens. Relevant policies must be formulated. The state must also make sure the approachability and accessibility of the policies. The current study showed that no respondents were accessible to any government policies in favor of children with intellectual disability.

6. FURTHER AREAS FOR RESEARCH

The finding of this study mainly concentrates on the impact of special school education. Even though the children were adults, they were not able to generate income and their dependency on care giver were high especially the financial burden because of poor economic status. The government policies and benefits in favor of ID children and its applicability and proximity in India could be a topic for further study.

7. CONCLUSION

Evidence clearly states that Primary Care Givers go through different types of hardships, distress and burden on physical, mental, psychological, social, emotional and financial aspects. The burden or distress varies from person to person according to the gravity of the disability and care recipient's ability to manage by oneself. No matter the perception brings the change. If the care giver, mostly the immediate family members, perceives their task with a collective responsibility of the family then, the enormity of challenges decreases.

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