



## Family Burden And Subjective Well Being in Family Caregivers of Persons With Intellectual Disability

### KEYWORDS

Family Burden , Subjective Well Being, Family Caregivers , Intellectual Disability

**Dr. SUJA. M.K**

Associate.Professor and HOD - Social Work / Counsellor, Director - Centre for Research & Development  
CMS College of Science & Commerce, Chinnavedampatti, Coimbatore -6410049, Tamil Nadu, India.

**ABSTRACT** *This research work aims to study the 'Family Burden and Subjective Well-Being of Family Caregivers of Persons with Intellectual Disability. The Research Design used for the study was Descriptive in nature. The universe consisted of family caregivers who visited an agency in Coimbatore, Tamil Nadu, India. The sampling technique adopted for the selection of the respondents was Non Probability - Purposive Sampling method. Sample size was 112. The tool used for this study was an Interview Schedule which had two standardized scales. The findings of the study reveal that Age, Gender, Family Monthly Income, Domiciliary and Duration of Disability influence the Family Burden and Subjective Well Being of Caregivers. It is also seen that as Family Burden increases Subjective Well-Being of the caregiver's decreases. The study also yielded some interesting results which implicate the scope for social work practice and further research in this area.*

### Introduction

This research work makes an attempt to study the Family Burden and Subjective Well Being in Family Caregivers of Persons with Intellectual Disability. Persons with Intellectual Disability impose considerable burden on their caregivers which include multiple responsibilities such as financial cost, physical care of the person and compromises on the freedom and leisure activities of the caregiver. Intellectual Disability has been given importance and many studies have been done in this area. But the caregivers are a neglected lot especially in India. Most of the Intellectually Disabled are taken care at home due to financial constraints. The burden of caring for the person with a disability falls on the family members because family ties, cultural values and unsaid code of ethics point towards the responsibility of the family members towards the disabled. Most of the family caregivers do not get respite from care. Having a life of their own and spending time for leisure and recreation is seen as a sin by the society. It is often ridden by guilt. Therefore the researcher felt it a problem of significance in the present scenario.

### Intellectual Disability

Intellectual Disability is a developmental disability that first appears in children under the age of 18. It is generally recognized as the child reaches school going age. The term used when a person has certain limitations in mental functioning and in skills such as communicating, taking care of him or herself, and social skills. These limitations will cause a child to learn and develop more slowly than a typical child. Children with Intellectual Disability may take longer to learn to speak, walk, and take care of their personal needs such as dressing or eating. They are likely to have trouble learning in school. There are four broad categories of Intellectual Disability based on approximate IQ: (1) Mild, (IQ 50-70), (2) Moderate, (IQ 35-50), (3) Severe, (IQ 20-35) and (4) Profound (IQ below 20). It is defined as significantly sub average general intellectual functioning existing concurrently with deficits in adaptive behaviour and manifested during the developmental period. Intellectual Disability is characterized by three criteria: Significantly sub average intellectual functioning, Concurrent and related limitations in two or more adaptive skill areas, Manifestation before age 18.

### Family Caregiving

A family member, relative, friend or neighbour who provides practical, day-to-day unpaid support for a person unable to complete all of the tasks of daily living. The person who receives care is the care recipient, defined as a person who lives with some form of chronic condition that causes difficulties in completing the tasks of daily living. (Savage and Bailey 2004) Family caregivers in this study are family members or relatives of the care recipient.

### Impacts of Caregiving on the Caregiver

Caregiving almost always impacts on the life of the caregiver. (Goodhead and Mc.Donald, 2007) Those heavily involved in caregiving, experience profound and wide-ranging changes to their lives. In studies that compare caregivers with others, caregivers often report poorer physical health and higher use of medication than others. In many studies caregiving is associated with increased rates of depression and anxiety, less life satisfaction and a feeling of being burdened. There is some evidence to suggest cognitive impairment and mental illness in the recipient are more burdensome for caregivers than physical problems. In general, impacts on a caregiver's mental health become greater as the time spent on caregiving increases.

Despite the demands of caregiving, reviewed literature show that most caregivers provide care gladly and feel positively about the role. However, those who have heavier caregiving commitments are more likely to feel negatively. All caregivers are more positive when they have help from others. (Goodhead and Mc.Donald, 2007). Increasingly, the literature on families and disabilities also emphasizes this adaptive capacity of families. It has been called family resilience. Many families actually report that the presence of disability has strengthened them as a family-they become closer, more accepting of others, have deeper faith, discover new friends, develop greater respect for life, improve their sense of mastery, and so on. (Patterson, 1991; Singer and Powers, 1993; Turnbull et al., 1993).

### Family Burden

Burden is any negative impact to the family caused by caring for an ill member. (Grad and Sainsbury, 1966) Furthermore, burden was divided into objective burden and sub-

jective burden (Hoenig and Hamilton,1966). Hoenig and Hamilton defined objective burden as an event or activity associated with negative caregiving experiences, whereas subjective burden referred to the feeling that appeared in the caregiver caused by the fulfillment of the caregiving function. Family Burden is the burden or difficulties faced by the family due to caring for a person with disability. (Pai and Kapur, 1981)

### Subjective Well-Being

Subjective Well-Being refers to a person's own assessment of their happiness and satisfaction with life. The cognitive element refers to what a person thinks about their satisfaction in global terms (life as a whole) and in domain terms (in specific areas of life such as work, relationships, etc.) The affective element refers to emotions, moods and feelings. Affect is considered positive when the emotions, moods and feelings experienced are pleasant. Affect is deemed negative when the emotions, moods and feelings experienced are unpleasant. (Diener, Lucas, and Oshi, 2002).

### Research Methodology

The research work aimed to study the Family Burden and Subjective Burden of Family Caregivers of Intellectually Disabled. The **Objectives of the study** was to understand the Socio Demographic Profile of the Respondents, To understand the Socio Demographic Profile of Persons with Intellectual Disability, To analyse the Level of Family Burden and Subjective Well – Being, To correlate the socio-demographic profile with the key variables and to find out the relationship between the Key Variables.

The **Research Design** used for the study is Descriptive in nature. **Pilot Study** was done during the month of May & June 2009. In order to find out the validity of the Interview Schedule a **Pretest** was conducted with 10 respondents. It was carried out in February 2010. The **Universe** consisted of family caregivers who visited the agency named SAARATHY PAMMAC (Parents Association for Persons with Mental Retardation, Multiple Disabilities, Autism and Cerebral Palsy, Coimbatore, Tamil Nadu, India.) during the period of data collection. The **Sampling Technique** adopted for the selection of the respondents was Non Probability - Purposive Sampling method. Sample size was 112.

The **Tool** used for this study was an Interview Schedule which had two standardized scales namely 1.Family Burden Scale by Pai and Kapur(1981). Reliability of the scale was reported to be more than 0.78(Cronbach Alpha) by the authors, which indicates a satisfactory reliability. 2.Subjective Well- Being Inventory by Nagpal and Sell (1992). ). Reliability of the scale is reported to be 0.84 (Cronbach Alpha) which shows high reliability.

The **Criterion for selecting the respondents** was that they should be family members or relatives of persons with Intellectual Disability. Other disorders like autism, cerebral palsy etc were excluded. **Data Analysis** was done using SPSS. Analysis included Simple Percentage, Significance Test 't', ANOVA and Correlation Matrix.

### Results and Discussion

#### 1. Socio-Demographic Profile of Respondents

Majority (42.9%) of Caregivers belong to the age group of 31-40years, 66.1% are females, 87.5%are parents, 52.7% have educational qualification below 10<sup>th</sup> standard , 78.6% are married, 38.4%are housewives, 62.5% have family monthly income upto Rs.5000, 53.6% are from urban area,

61.6% are from nuclear family, 80.4% have no health problem, 61.6% have another person to take care of their ward in their absence, 76.8% are fully aware of their ward's illness/condition, 76.8%do not believe in indigenous method of treatment,65.2% have not tried indigenous method of treatment.

#### 2. Socio-Demographic Profile of Clients (Persons with Intellectual Disability)

It is seen that 54.46% of clients have Mild Intellectual Disability. As far as age is concerned 73.2% with Intellectual Disability fall below the age group of 20 years and 62.5% are male, Educationally 55.4 % fall under Not Applicable which means they are either illiterate or not in a condition to go to school. Majority (43.8%) are the first child in the family.33% of the clients were diagnosed with Intellectual Disability during 2 months to1year of age and 25% have the disability for 11-15 years. Majority (50.9%) of the clients with Intellectual Disability are cared for at home. Majority (59.8%) of parents of clients are close relatives (Consanguineous Marriage).

#### 3. Level of Family Burden

**Table No: 1 –Distribution of respondents by Level of Family Burden**

S.No	Family Burden Score	TOTAL	
		No.	%
1	Low	70	62.5
2	Moderate	34	30.4
3	High	8	7.1
TOTAL		112	100.0

Majority of the respondents (62.5%) have low level of Family Burden. Heller and Hsieh (1997) found that formal supports can help caregivers by providing additional help which alleviate distress. Keer and McIntosh (2002) state that informal supports like parental groups can relate to one another's situation and can help provide social, emotional and physical support which in turn can reduce family burden of caregivers. The study reveals low level of family burden in the caregivers of Intellectually Disabled. All the respondents were selected from a parental group (Sarathi PAAMAC) and they have self help groups which meet once a month and conduct sales of products like homemade eatables, sari, handicrafts etc. It is a place and time for relaxation and exchange of ideas. This may be the reason why majority of the respondents (62.5%) have low Family Burden.

#### 4.Level of Subjective Well-Being

**Table No: 2- Distribution of respondents by Level of Subjective Well - Being**

S.No	Subjective Well - Being Score	TOTAL	
		No.	%
1	Low	1	.9
2	Moderate	39	34.8
3	High	72	64.3
TOTAL		112	100.0

Majority of respondents (64.3%) have high level of Subjective Well-Being. Tarlow et al., (2004) report that caregiving makes the carer's feel good about themselves, gives meaning to their lives and strengthens their relationships. All this can lead to higher subjective well being in carer's. Heiman (2002) indicates that strong belief in the child and the child's future, an optimistic outlook and a realistic view and acceptance of the disability lead to resilience and coping. This may be the reason why the results in this study indicate that majority of carers of persons with intellectual disability have high level of subjective well being. According to (Patterson 1991, Singer Powers 1993 and Turnbull et al. 1993), family care givers have found ways to cope with added stress in their lives. Adaptive capacities of families have increased. It is called family resilience. Many families report that the presence of disability has strengthened them. They became closer, accepted others, had deeper faith, improved their strength of mastery, discovered new friends and developed greater respect for life.

### 5. Socio-Demographic Correlates of Family Burden

**Table No: 3- Family Burden and its influencing factors**

S. No	Variable	't' / ANOVA	Significance
1	Age	ANOVA	**
2	Gender	't' Test	NS
3	Family Monthly Income	ANOVA	*
4	Domiciliary	ANOVA	**
5	Order of Birth	ANOVA	NS
6	Duration of Disability	ANOVA	**

NS- Not Significant , \* - Significant at 5% , \*\* - Significant at 1%

Caregivers above 50 years, who are from lower income families and who come from rural domicile have higher Family Burden. Family Burden is also higher among respondents who take care of clients with disability of more than 20 years. The researcher on interaction with the caregivers found that as the caregivers grow older their abilities to meet the demands of caregiving reduces. They are stressed and worried about the client's future thus increasing the family burden. It is seen that family burden is more in caregivers who have income upto 5000. Upadhyaya and Havalappanavar (2008) report higher levels of financial stress in lower income families. In this study rural families faced more family burden which is in contrast to the findings of Milofsky (1980) which states that families in rural areas tend to rely more on informal relationships, as they come to know and care for each other. This may be due to the fact that Indian rural condition is not similar to that of other countries. Moreover in Indian rural set up the proximity with neighbours, their enquiries about the family members add upto the Family

Burden. Harris and Mc.Hale (1989) state that family problems were associated with more time spent with disabled child. Petit (2006) report that as mentally challenged individual reaches adulthood the caregivers financial stress level tends to increase.

### 6. Socio-Demographic Correlates of Subjective Well-Being

**Table No: 4- Subjective Well - Being and its influencing factors**

S. No	Variable	't' / ANOVA	Significance
1	Age	ANOVA	*
2	Gender	't' Test	**
3	Family Monthly Income	ANOVA	**
4	Domiciliary	ANOVA	NS
5	Order of Birth	ANOVA	NS
6	Duration of Disability	ANOVA	NS

NS - Not Significant , \* - Significant at 5% , \*\* - Significant at 1%

Subjective well-being of caregivers above 50 years are lower than other age groups. Male caregivers showed higher subjective well-being than female caregivers and higher income groups had higher subjective well-being. According to Lawton et al., (1992) age associated impairments in physical competence make the provision of care more difficult in older caregivers. Yamaki et al.,(2009) stated that psychological well being of older caregivers were poor when compared to non carers. Tsai and Wang (2009) reported mothers of children with intellectual disability had higher levels of strain. Orsmond et al., (2003) reported that behaviour problems in mentally retarded children predicted changes in maternal well being. Montgomery et al.,(1985) report income as the best predictor of subjective burden. This may be the reason for lower Subjective Well Being of the caregivers in this study.

### 7. Correlation Between Family Burden and Subjective Well-Being

**Table No: 5 - Correlation between Family Burden and Subjective Well - Being**

Variables	Family Burden Score	Subjective Well Being Score
Family Burden Score	1.000	-.445**
Subjective Well Being Score		1.000

\*\* - Significant at 1%

It is seen that there is good negative correlation between Family Burden Score and Subjective Well Being Score. It indicates that as Family Burden increases Subjective Well Being decreases.

### Conclusion

**Implications for Social Work Practice:** Caregivers of Intellectually Disabled with high and complex needs would benefit from a holistic assessment of the family, well coordinated services, flexible support packages and a planned of the young person into adulthood and quality respite home services. Aged and women Caregivers would benefit from Respite Care which provides them some rest and leisure. Respite Care services need to be increased especially in the city where the study was conducted. Group work as method of Social Work would benefit the Caregivers, as they would find a common platform to share and ventilate their feelings. Support from other caregivers would alleviate stress and induce a feeling of belongingness and well being. It was felt from the researchers interaction with the

respondents that, Caregivers want

different information at different points of time after the onset of disability. Provision of information should be an ongoing process covering all aspects relevant to caring and tailored to the needs of caregivers and clients. Provision of printed information is insufficient. Short training workshops would be more effective than an information booklet. On the whole Interventions focusing of Positive Coping could improve the Subjective Well Being and Holistic Health of the caregivers and hence reduce the Family

Burden. So there is always a need for intervention towards alleviating their distress.

## REFERENCE

- Ahuja, Niraj,(2011) Concise textbook of Psychiatry. New Delhi, India: Himalaya Publications. | •Diener, E., Oishi, S., & Lucas, R. E. (2002). Subjective well-being: The science of happiness and life satisfaction. In C.R. Snyder & S.J. Lopez (Ed.), *Handbook of Positive Psychology*. Oxford and New York , Oxford University Press. | •Goodhead, A., and McDonald, J. (2007). *Informal caregivers literature review* (Tech Rep). New Zealand: Victoria University of Wellington, Health Services Research Centre. Downloaded from :[www.moh.govt.nz/moh.nsf/.../informal-caregivers-literature-review.pdf](http://www.moh.govt.nz/moh.nsf/.../informal-caregivers-literature-review.pdf) | •Grad, J., and Sainbury, P. (1966). Problem of caring for the mentally ill at home. *Proceeding of the Royal Society of Medicine*, Vol. 59(1), 20-23. ISSN:0141-0768 | •Harris, V.S., McHale, S.M. (1989). Family life problems, daily caregiving activities and the psychological well-being of mothers of mentally retarded children. *American Journal of Mental Retardation*, Vol.94(3),231-239. ISSN: 0895-8017. | •Heiman.,T.(2002).Parents of Children with Disabilities: Resilience, Coping, and Future Expectations. *Journal of Developmental and Physical Disabilities*,Vol.14,(2),159- 171. ISSN Print: 1056-263X. ISSN Online: 1573-3580. DOI: 10.1023/A:1015219514621 | •Heller,T., Hsieh,K., and Rowitz,L. (1997). Maternal and paternal care giving of persons with mental retardation across the lifespan. *Family relations: Interdisciplinary journal of applied family studies*, Vol.46(4), 407-415. ISSN: 0197-6664. | •Hoening, J., and Hamilton, M. W. (1966). The schizophrenic patient in the community and his effect in the household. *International Journal of Social Psychiatry*, Vol. 12, 165-176. ISSN: 0020-7640. | •Kerr, S.M., and McIntosh, J.B. (2000). Coping when a child has a disability: Exploring the impact of parent-to-parent support. *Journal of Child Care, Health, and Development*, Vol. 26(4), 309-321. ISSN. 0305-1862. | •Lawton,M.P.,Rajagopal,D., Brody,E.,and Kleban,M.H.(1992).The Dynamics of Caregiving for a demented elder among Black and White Families. *Journal of Gerontology: Social Sciences*, Vol.47,156-164. ISSN:1079 5014 | •Milofsy,Carl. (1980). Serving the Needs of Disabled Clients: A Task-Structured Approach. *Journal of Social Work*, 149-152. Print ISSN: 1468-0173; Online ISSN: 1741-296X. | •Montgomery, R.J.V., Gonyea J.G., and Hooyman, N.R. (1985). Caregiving and the experience of subjective and objective burden. Retrieved from: <http://www.jstor.org/jstor/gifcvtidir/ap001429/01976664/ap020022/02a00030> | •Nagpal,R., and Sell,S. (1992). Subjective Well - Being Inventory (SUBI) ,SEARO Regional Health Paper No: 24, New Delhi: World Health Organisation. | •Orsmond Gael. , Marsha Lailick Krauss ,Marty Wyngaarden and Hong Jinkuk. (2003). Behavior problems in adults with mental retardation and maternal well-being: Examination of the direction of effects. *American Journal On Mental Retardation*,Vol.108( 4), 257-271. ISSN: 0895-8017. | •Pai,S., and Kapur,R.L.(1981). The burden on the family of a psychiatric patient: development of interview schedule. *British Journal of Psychiatry*,Vol.138,332-335. Online ISSN: 1472-1465; Print ISSN: 0007-1250. | •Pai, S., and Kapoor, R.L. (1983). Evaluation of home care treatment for schizophrenia. *Acta Psychiatrica Scandinavica*,Vol.67, 80-88. ISSN: 0001-690X | •Patterson, J. (1991). Family resilience to the challenge of a child's disability. *Paediatric Annals*, Vol. 20(9),491-499. Print ISSN: 0090-4481. Online ISSN: 1938-2359 | •Petit,J.R.(2006). Deinstitutionalization: the consequences for the primary caregiver. The University of Texas at Arlington, United States. Retrieved from:50201-1153849531-Jenn\_S\_Thesis. | •Savage, S., and Bailey, S.(2004). The impact of caring on caregivers' mental health: a review of the literature. *Australian Health Review*, Vol. 27(1), 111-117. ISSN: 0156-5788 | •Singer, G.H.S.,and Powers,L.E.( 1993) Contributing to Resilience in Families: An Overview. In: Singer GH, Powers. L.E eds. *Families, Disability, and Empowerment: Active Coping Skills and Strategies for Family Interventions*. Baltimore, P.H.Brookes Publications, 1-26. | •Tarlow,B.J., Wisniewski,S.R., Belle,S.H., Rubert,M., Ory,M.G., and Thompson,D.G.et al. (2004). Positive aspects of caregiving: Contributions of the REACH project to the development of new measures for Alzheimer's caregiving. *Research on Aging*, 26(4), 429-480. Print ISSN: 0164-0275; Online ISSN: 1552-7573. | •Tsai, S.M., and Wang, H.H. (2009). The relationship between caregiver's strain and social support among mothers with intellectually disabled children. *Journal of Clinical Nursing*, Vol.18(4), 539 – 548. ISSN: 1365-2702 | •Turnbull, A.P.(1993). Cognitive coping, families, and disability. Baltimore,U.S.A, P.H. Brookes Publications. | •Upadhyaya, G.R., and Havalappanavar,(2008).Stress in Parents of the Mentally Challenged. *Journal of the Indian Academy of Applied Psychology*,Vol. 34(2) 53-59. ISSN: 0019-4247 | •Yamaki, Kiyoshi., Hsieh, Kelly., and Heller,Tamar. (2009).Health profile of aging family caregivers supporting adults with intellectual and developmental disabilities at home. *Journal of Intellectual and Developmental Disabilities*. ISSN: Print-1366-8250, Online:1469-9532 |