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RESEARCH ARTICLE

PSYCHOSOCIAL BURDEN ON PRIMARY CAREGIVERS OF CHILDREN WITH DOWN SYNDROME

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Abstract

Down syndrome is the commonest chromosomal disorder causing mild to moderate intellectual disability. A child with disability is a serious stress factor for parents. In India persons with intellectual disability have traditionally been cared for by their families. Multifaceted factors have made parenting vulnerable to stress. Indian studies are lacking on care arrangements of children with Down syndrome and their caregiver's psychological issues. A cross sectional study was conducted to assess care arrangements of children with Down syndrome and caregiver burden and depression. 70 caregivers of children less than 18 years attending the Down syndrome clinic at Government Medical College Hospital, Thrissur from January 2013 to July 2014 were enrolled in the study. Subjects were interviewed by questionnaire method using internationally accepted measuring tools like client service receipt inventory, burden interview, caregiver activity survey and general health questionnaire. Mothers were the primary givers in 69(99%) of cases. 29(40%) caregivers experienced moderate to severe burden. Depression was detected in 44(63%). There was a significant positive correlation between caregiver burden and level of depression (correlation coefficient 0.62, p value 0.001). Severe burden was reported in caregivers having children with hypothyroidism (p value-0.026) and hearing impairment (p value-0.001). Depression was more prevalent in older mothers (p value-0.05) but less in mothers who were better educated (p value-0.005) and those who were employed (p value-0.03).

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Introduction:-

Down syndrome is the commonest chromosomal disorder causing mild to moderate intellectual disability. The worldwide incidence is 1 in 733 live births (1). A mentally retarded child in a family is usually a serious stress factor for parents. It often requires reorientation and re-evaluation of family goals, responsibilities and relationships (2). Multifaceted factors like social isolation, financial constraints, poor marital relationships, behavioral, health and developmental problems of the child and above all limited family and social support have made parents vulnerable to stress. In India the majority of persons with intellectual disability have traditionally been cared for by their families (3).

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Parents of children with Down syndrome perceived more care giving difficulties and child related stress like distractibility, demanding or unacceptable behavior. Parent related stress like incompetence, depression and health problems were also more in these parents (4).

Children with Down syndrome when intervened early by speech therapy, physiotherapy and occupational therapy and given proper medical attention for different health issues, can have a better long term outcome as compared to other genetic causes of intellectual disability.(5). Hence the need for their long term care .But this also poses challenges to the caregivers and adds to their emotional and social stress. Indian studies done were mainly on caregivers of children with intellectual disability as a broad category which also included Down syndrome. Hence this study was planned on care arrangements of children with Down syndrome and the caregiver's psychological issues and is probably the first of its kind from South India done solely on caregivers of children with Down syndrome.

Materials and Methods:-

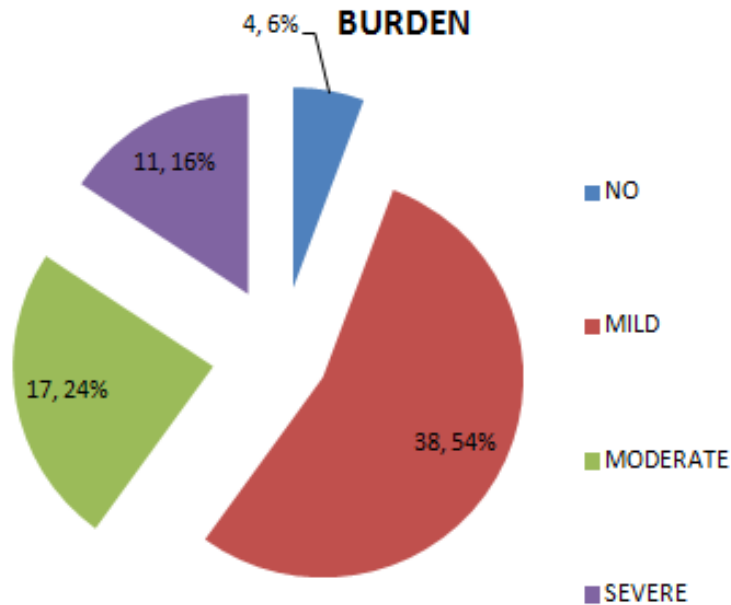
A cross sectional study was done on 70 caregivers of children below 18 years attending the Down syndrome clinic at Government Medical College Hospital(GMCH),Thrissur from January 2013 to July 2014 ,a period of one and a half years . Subjects were interviewed by questionnaire method using internationally accepted research methods and measuring tools, which included *client service receipt inventory*, *burden interview*, *caregiver activity survey* and *general health questionnaire*. Data was obtained by personal interview using standard proforma and consent, from caregivers of children attending Down syndrome clinic at GMCH, Thrissur. *Client service receipt inventory (CSRI)* is a research method and instrument for the collection of data on service utilization and related characteristics of people with mental disorders as the basis for calculating the cost of care. . It is a questionnaire for collecting retrospective information about study participant's use of health and social care services, usual living situations, employment and income, service receipts and medication profile(6) *The Zarit Burden Interview* has been specially designed to address the stresses experienced by caregivers of patients with dementia and chronic illnesses . It consists of a set of 22 questions to the caregivers for assessing the impact of the patient's disabilities on their life. Higher scores indicate greater caregiver distress(7). *The Caregiver Activity Survey (CAS)* is a tool developed to measure the time caregivers spend aiding Alzheimer's patients with their day-to-day activities and this would help to determine the economic impact of the illness(8). *The General Health Questionnaire* is a method to quantify the risk of developing psychiatric disorders. The instrument targets on the inability of the caregiver to carry out normal functions and the appearance of distress in order to assess well being in a person. The format is 60 item test (9). The test exists in several alternate forms: GHQ-30(30 items), GHQ-28 and GHQ-12. In this study the GHQ 12 version was employed to assess depression. The advantage of GHQ 12 is that it can be used in busy clinical settings and in situations where the patients are illiterate ,the questionnaire can be read out to them(10).These tools were modified suitably to use in caregivers of disabled children. Data was analysed using SPSS version 18.

Results:-

A total of 70 caregivers were interviewed. The median age of the children cared for was 4.5 years and the male to female ratio was almost equal. Mothers were the primary caregivers in all families.. Grandparents were informal carers for 32 (46%) and mothers sole caregivers for the rest 38(64%). 40 mothers (57.1%) were more than 30 years at the time of delivery .Even though 51(73%) mothers had up to secondary education and above, only 20(29%) were working. Out of 22 working mothers, 14(63%) had to quit or cut down their working hours. The majority of children (68 , 96%) stayed with their parents .Out of the 38 children attending school 24(73%) went to normal schools and 14(27%)to special schools.Only 33 (47%) received any financial assistance from the government.Living conditions of many were not satisfactory. Overcrowding was found in many homes. Among the daily caregiver activities, feeding was reported to be the most time consuming part.

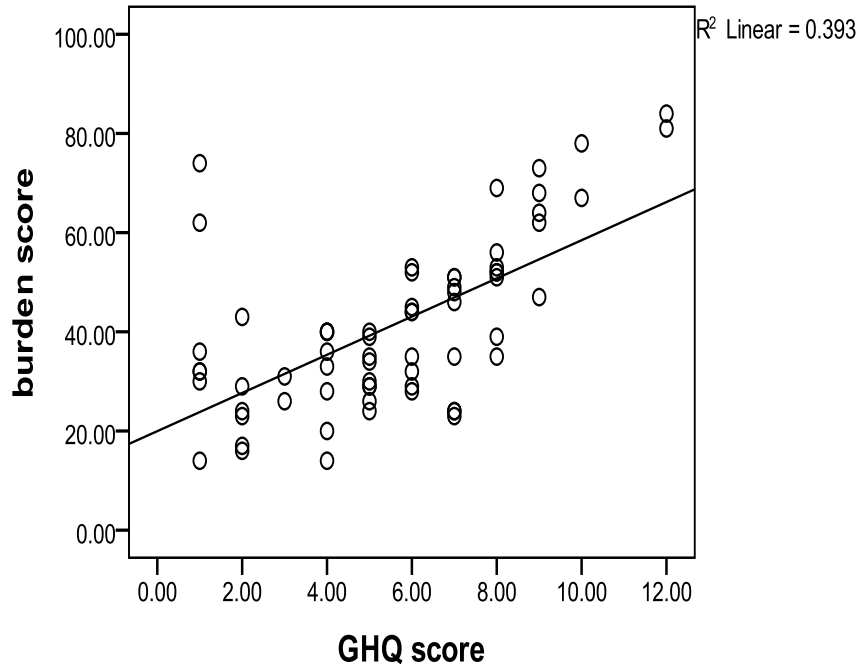
Severe burden was perceived in 11(16%), moderate burden in 17(24%), and mild burden in 38(54%). 4 (6%) caregivers perceived no burden which was assessed using Zarit Burden Interview Score.

Figure 1:- Severity of burden in caregivers as per Zarit Burden Interview.

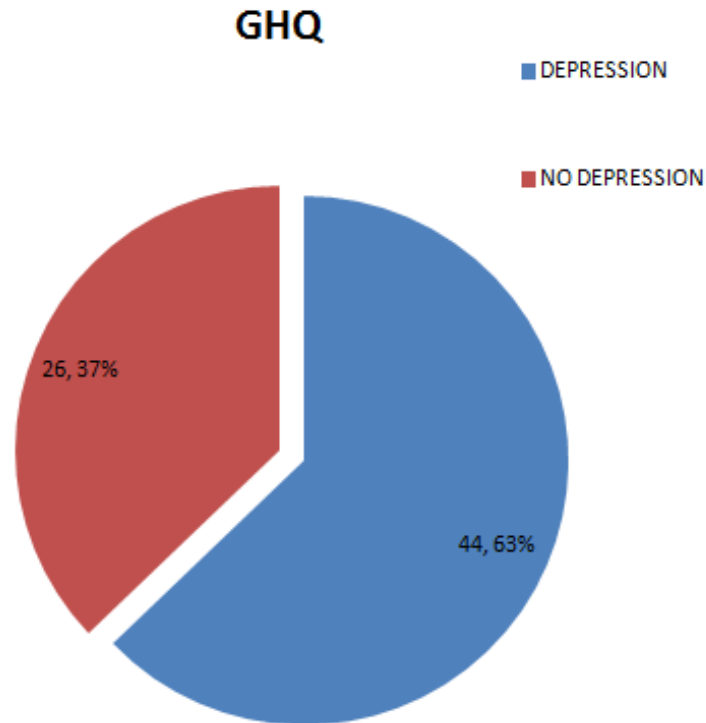


A positive correlation was seen between increasing burden (Zarit burden interview score) and level of depression (General health questionnaire score). (correlation coeff-0.62 ,p value-0.001) .

Figure 2:- Correlation between burden interview score and general health questionnaire score(GHQ).



Caregiver depression was detected in 44(63%) cases according to general health questionnaire 12 score.

Figure 3:- Caregiver Depression As Per General Health Questionnaire (Ghq).

Hypothyroidism (p value-0.026) and hearing impairment (p value-0.001) in children imparted severe burden to their caregivers. Severe burden was not reported by caregivers with friend's or relative's help (p value-0.005). Child needing more assistance in their daily activities increased burden of the caregiver (p value-0.035).

Depression was also found to be more associated in caregivers of children with hypothyroidism (p value-0.005) & hearing impairment (p value-0.005). It was more prevalent in older mothers than younger ones (p value-0.05) and less in better educated mothers (p value-0.005) and caregivers who continued with their jobs (p value-0.030).

Discussion:-

Most children in the study group were cared for at their homes and mothers were the primary caregivers in almost all cases. Among the mothers about two third were the sole caregivers and hence they alone had to bear the entire burden of care giving. For this, many had to quit or cut down their jobs. Among the children attending school, three fourth went to normal school which shows a change in outlook among people towards disability with their community and educational inclusion rather than segregation. Less than half received financial assistance from the government. Medical professionals need to be sensitized about the burden on the caregiver so that they adopt a more favourable approach while issuing disability certificates and pensions. About 40% of caregivers experienced moderate to severe burden. In a study from India by Bhatia et al (2015) severe burden was detected in 39% of caregivers of mentally disabled children (11). Depression was found in 63%. Prevalence of depression was 70% in a study from Pakistan by Azeem et al (2013) on parents of children with intellectual disabilities (2). But in a European study by Van Riper et al the rate of depression was 30% which was comparatively lesser (12). This could be due to better economic and educational status of caregivers and their constant contact with the health care system. There they have support groups that allow sharing, contact with each other, provide information about the child's condition and assistance in choosing healthy coping strategies (12).

A positive correlation was found between caregiver burden and depression. It could be that the increasing burden contributing to depression or the depression among caregivers that made them feel burdened. In an Australian study, Jenna Serr, BS et al (2007) also found positive correlation between depression and caregiver burden. They also found that burden was more in mothers compared to fathers (13). Children with more disabilities caused more burden

and depression among caregivers (14,15,16).Hearing impairment and hypothyroidism in children increased the burden of caregivers, may be the hearing impairment causing difficulty in communication and hypothyroidism further contributing to worsening of their cognitive impairment.

Age of the mother was found to be significantly associated with depression. Older mothers perceived more depression than younger ones. But Anna J Esbensen et al(2011)in her study on North American parents found older maternal age at the time of birth of the child ,experienced less depression and better well being compared to younger mothers. It could be attributed to greater maturity and financial stability and larger social support networks among older mothers there(17).

Better educated and working mothers were less burdened and depressed. In a study by Cuskelly M et al (2014) similar finding was obtained where older and better educated parents and constant contact with health care services were associated with less depression(14).Sujatha sethu et al (2013)in her study from India found that parents' education and economic status of the family did not make any difference to the perceived stress and burden(18,19). Working mothers reported less stress and more life satisfaction despite the extra demands of work, child care and family. Working outside provided mothers with social contacts and friends, a different role, a change of daily demands and an increase in income.(4). Presence of relative's (informal carers) help was associated with lesser degree of caregiver burden. Feldman M et al (2011)in his study also had similar experiences(20,21).

Conclusions:-

Mothers are the sole caregivers in our country and they have to be involved in activities apart from care giving. Strategies focussing on the physical, mental and psychological wellbeing and upliftment of mothers have to be adopted. Fathers and other family members have to be motivated to play better roles in the care of their child with disability. The community also should be involved and support systems and groups created to reduce the burden on the caregiver. Preventive health care guidelines have been made available to both parents and doctors . Health facilities for the differently abled in government sector have to be improved ; so also the awareness and utilization of existing services Registries have to be created for different types of disabilities The caregiver should also to be included as a recipient of care.

References:-

1. Marcdante KJ, Kliegman, Nelson WE. Nelson essentials of pediatrics [Internet]. 2015 [cited 2014 Oct 21].
2. Azeem MW, Dogar IA, Shah S, Cheema MA, Asmat A, Akbar M, et al. Anxiety and Depression among Parents of Children with Intellectual Disability in Pakistan. *J Can Acad Child Adolesc Psychiatry*. 2013 Nov;22(4):290–5.
3. Majumdar M, Da Silva Pereira Y, Fernandes J. Stress and anxiety in parents of mentally retarded children. *Indian J Psychiatry*. 2005;47(3):144–7.
4. Roach MA, Orsmond GI, Barratt MS. Mothers and fathers of children with Down syndrome: parental stress and involvement in childcare. *Am J Ment Retard*. 1999 Sep;104(5):422–36.
5. Agarwal Gupta N, Kabra M. Diagnosis and management of down syndrome. *Indian J Pediatr*. 2014 Jun;81(6):560–7.
6. Chisholm D. Client Socio-Demographic and Service Receipt Inventory - European Version : development of an instrument for international research: EPSILON Study 5. *Br J Psychiatry*. 2000 Jul 1;177(39):28s – 33.
7. Zarit Burden Interview- (BI) / (ZBI) [Internet]. [cited 2014 Oct 25]. Available from: <https://instruct.uwo.ca/kinesiology/9641/Assessments/Psychological/ZBI.html>
8. Marin DB, Dugue M, Schmeidler J, Santoro J, Neugroschl J, Zaklad G, et al. The Caregiver Activity Survey (CAS): longitudinal validation of an instrument that measures time spent caregiving for individuals with Alzheimer's disease. *Int J Geriatr Psychiatry*. 2000 Aug;15(8):680–6.
9. Jackson C. The General Health Questionnaire. *Occup Med*. 2006 Aug 23;57(1):79–79.
10. Goldberg DP, Gater R, Sartorius N, Ustun TB, Piccinelli M, Gureje O, et al. The validity of two versions of the GHQ in the WHO study of mental illness in general health care. *Psychol Med*. 1997;27(01):191–7.
11. Bhatia MS, Bhatia S, Gautam P, Saha R, Kaur J, others. Burden assessment, psychiatric morbidity, and their correlates in caregivers of patients with intellectual disability. *East Asian Arch Psychiatry*. 2015;25(4):159.
12. Van Riper M, Ryff C, Pridham K. Parental and family well-being in families of children with Down syndrome: a comparative study. *Res Nurs Health*. 1992 Jun;15(3):227–35.

13. Jenna Serr BM. Linkages between depression and caregiver burden in parents raising children with disabilities. 2007;
14. Cuskelly M, Jobling A, Chant D, Bower A, Hayes A. Multiple Perspectives of Family Life. In: Cuskelly M, Jobling A, Buckley S, editors. Down Syndrome Across the Life Span [Internet]. Whurr Publishers Ltd; 2001 [cited 2014 Oct 23].p.159–73. Available from: <http://onlinelibrary.wiley.com/doi/10.1002/9780470777886.ch13/summary>
15. Motaghedi S, Haddadian M. The Effect of Growth appraisal & Individual Assessment of Stress on Mental Health of Autistic Children’s Parents. Life Sci J [Internet]. 2014 [cited 2014 Oct 22];11(9s). Available from: http://www.lifesciencesite.com/lj/life1109s/005_24680life1109s14_32_37.pdf 12
16. Muranjan MN, Budyal SR, Shah HR. Are Indian parents of children with Down syndrome engaged in the blame game? Indian J Pediatr. 2013 Jul;80(7):560–4.
17. Esbensen AJ, Seltzer MM. Accounting for the “Down Syndrome Advantage.” Am J Intellect Dev Disabil. 2011 Jan;116(1):3–15.
18. Sethi S, Bhargava SC, Dhiman V. Study of level of stress and burden in the caregivers of children with mental retardation. East J Med. 2013;12(1-2):21–4
19. Girimaji SC, Srinath S, Seshadri S, Krishna DKS. Family interview for stress and coping in mental retardation (FISC-MR): A tool to study stress and coping in families of children with mental retardation. Indian J Psychiatry. 1999;41(4):341–9.
20. O’Connor N, Kotze B, Wright M. Blame and accountability 1: understanding blame and blame pathologies. Australas Psychiatry Bull R Aust N Z Coll Psychiatr. 2011 Apr;19(2):113–8.
21. Feldman M, McDonald L, Serbin L, Stack D, Secco ML, Yu CT. Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay. J Intellect Disabil Res JIDR. 2007 Aug;51(Pt 8):606–19.