EFFECTIVENESS OF EDUCATIONAL PACKAGE ON EXPRESSED EMOTION, QUALITY OF LIFE AND BURDEN AMONG FAMILY MEMBERS OF MENTALLY HANDICAPTED - A REVIEW

Mr. Rajaemmanuel Solomon* | Dr. Balasubramanian N**
* Research Scholar in Himalayan University, Itanagar in Arunachal Pradesh, India.
** Research Supervisor in Himalayan University, Itanagar in Arunachal Pradesh, India.

ABSTRACT:
A review of literature provided researcher with the current theoretical and scientific knowledge about effectiveness of educational package on expressed emotion, quality of life and burden among family members of mentally handicapped and resulting in a synthesis of what is known and what is not known. Review of literature explains the research and non-research literature to broaden the understanding and gain insight into the selected problem under study. A review helped to lay the foundation for a study. It revealed that No satisfactory treatment is available till today. No drugs are available to increase the intelligence. Most of the intellectual disability children brought for treatment can only be benefited to a limited extent. It can be managed through primary prevention which includes health promotion, specific protection.

Key words: Emotional package, mentally handicapped, quality of life.

ABOUT AUTHORS:

Author, Mr. Rajaemmanuel Solomon is a Ph.D. Scholar at Himalayan University, Itanagar, Arunachal Pradesh, India.

Author, Dr. Balasubramanian N is Ph.D. Guide at Himalayan University, Itanagar, Arunachal Pradesh, India. He is active researcher with many publications in his name. He has attended and organised various National and International conferences.
INTRODUCTION:
There are some people who lack normal physical abilities. For example, there are people who are unable to see, hear or speak and some others who are unable to move around. These people are commonly termed as physically disabled. Similarly, there are individuals who have poor and insufficient development of mental functions which includes control over their body movements, their intelligence, social interaction and language from birth or early childhood. These people are termed as mentally handicapped.

An extensive review on care of mentally handicapped has been done from published articles, journals, pub med and internet to form a strong foundation for the study. Under the following heading, the researcher reviewed the literature. It is related to;

1. Mentally handicapped.
2. Literature related to Incidence and prevalence of mentally handicapped.
3. Literature related to diagnosis, management and prognosis of mentally handicapped.
4. Literature related to expressed emotion regarding care of mentally handicapped.
5. Literature related to quality of life regarding care of mentally handicapped.
6. Literature related to burden regarding care of mentally handicapped.
7. Literature related to effectiveness of educational package regarding care of mentally handicapped.

1. Mentally handicapped
The World Health Organization (WHO) reported that 10 – 20% of all the children have some kind of mentally handicapped. Normally parenting is a difficult job, but parenting with mentally handicapped children is a very tough task. There are so many negative stigmas which are related to mentally handicapped, so the family members are not aware about mentally handicapped in detail. Not all the mentally handicapped children are unique. The mentally handicapped children are differed with their problems like, difficulty in articulating, learning difficulties, forgetting, poor academic performance, low intelligence, poor IQ, behavioural problems, self-care deficit, drooling of saliva, not able to perform their daily activities, and poor attention span.

Reber M. (2012), stated that intellectual disability involves a general delay in the development of intellectual and adaptive abilities and affects most areas of social, cognitive and language functioning. Intellectual disability is generally assessed by a combination of testing on formal tests of intelligence and by observation of the child's adaptive functioning.

Chronic disability in children imposes great strain on the family. The responsibility of caring disabled children is a challenge to the wellbeing of caregivers. Thus, the caregivers of intellectual disability children are more vulnerable to stress. Hence given appropriate support, resources and education, primary caregivers of children with intellectual disability can cope with the challenges presented by their children and, in turn, provide a nurturing home environment. A nurturing home environment is a consistent predictor of success in school and subsequently in rehabilitation programs aimed at job training and increased independence.

2. Literature related to incidence and prevalence of mentally handicapped:
Intellectual disability is defined as someone having substantial, sub-average intellectual and adaptive behavioral functioning with onset before 18 years of age and limitations in at least two of the following areas; Communication, home living, social skills, community use, self-direction, safety, functional academics, leisure, work activities.

As stated by World Health Organization (WHO), (2013), approximately 156 million people or 3% of the World’s population are intellectually disabled.

Ahmad & Phalke, (2009), conducted a cross sectional study on health status and etiological factors of mentally challenged children in school for mentally challenged at Sangamner. In that study he mentioned that nearly 83 million of World’s population is estimated to be mentally retarded, in which 41 million are having long term or permanent disability. It ranks fourth in the list of causes of disability.

National Institute for the Mentally Handicapped (NIMH), (2013-2014), 30th annual report says, nearly 0.5 – 1% of all children in India are affected with intellectual disability. Intellectual disability can affect people from all walks of life. According to National institute for the mentally handicapped 30th annual report, among every one lakh persons in our total population, 124 persons are with intellectual disability. This translates to around 15 lakhs of affected persons presently in the country. According to the rehabilitation council of India’s (RCI) statistics, three per cent of Indian children below 14 years of age suffer from some form of intellectual disability. Nearly 70% of them live in the rural areas which have remained inaccessible to the Government’s rehabilitation programmes till date.
Sunil Kumar Raina, Sushil Razdan, and Renu Nanda, (2012), conducted a cross sectional study to determine the prevalence of mental retardation in children from 3 to 10 years of age in RS Pura town of Jammu and Kashmir. The results of the study include a total of 61(0.79%) of the 7,707 children surveyed had positive screening results on the Ten Questions Instrument, and 56(0.72%) children were diagnosed as suffering from mental retardation. Severe mental retardation was diagnosed in 48 children and mild mental retardation was diagnosed in 8 children. The mild and serious mental retardation prevalence estimates were 7.2/1000.

Daniel saí et al., (2015) conducted a descriptive study in Australia to assess the prevalence of mental retardation. In that 934 mentally retarded children were selected as samples and found that 79% of the children were suffering with mild mental retardation, 12% of children were with moderate type of mental retardation and about 9% of children were suffering with severe mental retardation.

Nair MKC, George B, et.al, (2009), conducted a cross sectional survey to identify the prevalence rates of developmental delay, deformity and disability among children up to 5 years of age in Pattanakad rural ICDS block, Alappuzha District, Kerala, India. In 191 anganwadis all under five age group are included as study samples. Developmental delay was assessed among babies up to 2 years of age using Trivandrum Developmental Screening Chart (TDSC) and above 2 years using Denver Developmental Screening Test (DDST). A total of 12520 children were noted as less than 5 years of age in Pattanakad ICDS block, as per records available with the anganwadi workers. In those 311 children with developmental delay, deviation, deformity or disabilities up to 2 years was 2.31% and from 2 to 5 years was 2.62%.

3. Literature review related to diagnosis, management and prognosis of mentally handicapped:
If mental retardation is suspected, a comprehensive physical examination and medical history should be done immediately to discover any organic cause of symptoms. If these conditions are discovered early, the progression of retardation can be stopped and, in some cases, partially reversed. If a neurological cause such as brain injury is suspected, the child may be referred to a neurologist or neuro psychologist for testing.

Clara DM, Karnebeek V, Schoper FY, Abeling NG, Alders M, et.al, (2005), conducted a study to assess the most effective diagnostic measure for a diagnosis of mental retardation. Prospective assessment following a stepwise protocol in 281 patients with unexplained cognitive delay was used to assess diagnostic possibilities. Diagnostic procedures were complex and require a multidisciplinary approach. One third of diagnoses were established based on clinical history and physical examination only; for another third, clinical history and physical examination provided essential clues for additional investigations only. The likelihood to reach a diagnosis did not depend on the severity of mental retardation. The study found that in tertiary care centre, a diagnosis can be established in 1 out of every 2 patients. Clinical history and physical examination is the most important instrument to reach a diagnosis.

People with mild to moderate intellectual disability are frequently able to achieve some self-sufficiency and to lead happy and fulfilling lives. To reach these goals, they need appropriate and consistent educational, community, social, family, and vocational supports. The outlook is less promising for those with severe to profound intellectual disability. Studies have shown that these persons have a shortened life expectancy. The diseases that are usually associated with severe intellectual disability may shorten the life span. Intellectual disability with Down syndrome will develop the brain changes that characterize Alzheimer’s disease in later life and may develop the clinical symptoms of this disease as well.

4. Review of literature related to expressed emotion regarding care of mentally handicapped:
Kingston, (2010). Investigated a cross sectional study to assess the knowledge of mothers regarding care of their intellectually defective child. In the study 226 mothers from different cultural background were included. Assessment was done by using formal questionnaire. Most of the mother had deficient knowledge on care of defective child. Many of the mothers considered their defective child as a burden and isolated in the house. They had poor knowledge regarding the home care, health problems, diet of the mentally retarded child. Report shows that 15% mothers had good knowledge 27% had moderate and 48% of mothers had very poor knowledge regarding care of defective child.

Tambu Jamison, (2010), had done an exploration of the quality of life of parent carers of children with intellectual disability in West Dublin, Ireland. Six parents of children with intellectual disability were selected with purposive sampling method. Result indicates that both negative and positive factors that affected the quality of life of the participants involved in this study. Even though these parents were experiencing some challenges in their caring of their children with intellectual disability, they were still happy with their lives and that of their children despite the amount and complexity of the caring involved.
Maryline Flinsi D, and Molly Babu, (2013), done a study to assess the role of parents in the care of mentally challenged children as perceived by parents and caretakers with a view to develop an information booklet regarding care of mentally challenged children in the selected schools of Tamilnadu. The findings revealed that there was a significant difference between the perception scores of parents and caretakers. The information booklet had high acceptability and utility among the parents and caretakers of mentally challenged children.

Ntswane AM, Rhyn VL, (2013), adopted a qualitative, exploratory, descriptive and contextual design to answer the research investigating experiences of care givers for intellectual disability children at home. Feelings of shock, despondency and sadness dominated the early stages, when the retarded children were young, during later years, as the children were growing up, the mothers felt shame, frustration, anger, disappointment and worry; when the child grew older they accept the condition. The study made recommendations regarding the improvement of health care service and education of mothers and other family members.

Sravan Kumar Sriram, (2014), revealed a study on awareness about mental retardation among regular school children. It was a comparative study and descriptive research design. In non-probability purposive sampling technique 200 samples were selected. The findings revealed that the students have awareness on mental retardation. There is a significance difference between the awareness levels of two schools towards mental retardation among normal school children.

Cad Bras Ter (2015) conducted a study on the relationship between expressed emotion and sociodemographic variables, early stress and stress symptoms in informal caregivers of people with mental disorders. 112 caregivers participated. Four instruments were used to collect data: socio-demographic questionnaire, the emotional over-involvement component of expressed emotion was significantly associated with early stress and stage of stress symptoms. Early stress, age, and the education level of caregivers were identified as predictive variables of high expressed emotion. These results confirm the relevance of these variables for the planning of care actions in the context of mental health.

VenkataKiran Vaddadi et al., (2015), explore a study to assess the knowledge of mothers regarding the care of mentally challenged children in selected schools at Guntur, Andhra Pradesh. The findings revealed that the 23.3% of the samples had moderate knowledge and 76.6% of the mothers of mental retardation children had adequate knowledge. It was implicated that mothers with mental retardation children should be educated about the impact of mental retardation and care of children affected with mental retardation.

5. Review of literature related to quality of life regarding care of mentally handicapped.

Bharat Singh Shekhawat, Supriya Agarwal, and Shreyance Jain (2015), conducted a comparative study on quality of life of caregivers of early-onset psychosis and mentally retarded children. QOL was significantly affected in most of its dimensions in the caregivers of both EOP and MR groups in comparison to the control group but more deterioration was noted in caregivers of children with MR. Sociodemographic factors such as domicile, education, family type, and family size were important determinants of QOL. Multiple factors seem to be responsible for poor QOL of caregivers of children with MR and EOP.

Hakeem MNL, Subathra V, (2013), conducted a study on the attitude of siblings towards their mentally retarded brother or sister. The study highlighted that family is the basic unit and every member influences and affects every other member in the family. It is mentioned that, when there is a mentally retarded child in the family the burden of the family increases. Even in families with typically developed children, sibling rivalry is a common factor. The problem can be multifold with mentally retarded children. Thus the study attempted to assess the attitude of their siblings among 60 respondents. Children between the age group of 5-9 years were selected for the study. The respondents were the siblings of mentally retarded children in day care centers in Coimbatore Corporation. But contrary to belief, the siblings had positive attitude towards their mentally retarded brothers and sisters and they have responded positively towards the future of their relationship.

Diane Joseph et al., (2014) conducted a study on mother’s attitude towards their intellectual disability children at cuddalore. 92 mothers from four special schools were selected as samples. The findings shows that the 68% of mothers have positive attitude towards their intellectual disability child and stated that mother’s educational status influenced their attitude and knowledge towards their children.

Sribas Goswami, (2013), explored the parental attitude of mentally retarded children in Kolkata. The researcher took 30 samples and out of 30 parents 27 were shown favourable attitude in above 50% of the total questions and 3 parents were identified with unfavourable attitude. The tool used for the study was 36 questions contain attitude scale. The 27 parents shown favourable attitude, but do not have 100% positive attitude.
Vidhya Ravindranandan, Raju S, (2007), studies the level of adjustment and attitudes of parents of children with mental retardation. Fifty parents from 25 to 50 years were selected as samples. An adjustment inventory, scale of parental attitude towards mental retardation was used. Results showed that the change in parental attitude between different religion. Locality affects only the dimensions of social adjustment and parental attitude. Mythili Hazarika, (2017), conducted a cross sectional descriptive study on parents attitude towards children and adolescents with intellectual developmental disorder. In the convenient sampling technique 66 parents with intellectual disabled children were selected and administered attitude questionnaire. The Likert scale was used with the theme of love and acceptance, embarrassment, frustration, disappointment and overprotection were assessed in the questionnaire. Findings revealed that the parents who accepts their child’s status of intellectual deficit and takes the help of rehabilitation centers have unfavorable attitude.

6. Review of literature related to burden regarding care of mentally handicapped.
Kuldeep Singh etal., (2014), had done a study of burden in parents of children with mental retardation. Study group showed significant higher level of burden than healthy control group. Therefore, it is very important that mental health professionals to take care for these populations as individuals. There is no doubt that mental retardation (MR) is a life-long disability with has a major impact on the lives of the children and their families. Flynt SW, Wood TA, (2012), conducted a cross sectional study regarding perceptions of family stress and coping behaviors of 90 mothers with moderately mentally retarded children. Measures of family stress and coping were administered to subjects with a retarded child in one of three normative transition periods. There were no significant differences in family stress scores. Significant differences were found for race and maternal age with regard to perceived stress. Significant differences in coping behaviors were found for race, marital status, and socioeconomic status also. RadheyShyam, Kavitha and DeepikaGovil (2013), conducted a study to assess and compare parenting stress and family burden in mothers of children with disabilities and children without disability. Mothers of children with mental disability, mothers of children with both mental and physical disability, mothers of children with physical disability, mothers of deaf and dumb children, and mothers of children without disability were selected as samples. Parenting stress index and family burden scale were administered on 125 mothers of children with disability and without disability (25 mothers in each group) were selected from three districts of Haryana State. Results revealed that mothers of children with both mental and physical disability and mothers of children with mental disability scored significantly higher level of parenting stress and family burden compared to mothers of children with physical disability, mothers of deaf and dumb children, and mothers of children without disability. Shukir.S.Hasan, Bokan Abd Muhammad (2015), had done impact of intellectual disability children upon parent’s quality of life. Overall the study found that both parents were under the burden, in addition to that the mothers were affected more than the fathers. Most mothers complained of psychosocial problems while fathers complained of the physical and social problems. ArpanaJadhav (2013) conducted a study of caregiver’s burden of mentally challenged children. It revealed that caregivers of mentally challenged children encounter different problems like, feeling of burden in care giving leads to stress and demands of daily care, lack of leisure time, emotional disturbances such as worries, frustrations, sadness, irritability and relationship problems between family members. In addition there is stigmatization, social embarrassment and financial implication. Planned teaching had significantly brought out their reduction in burden of care givers of mentally challenged children. Kermanshahi SM, Vanaki Z, et.al, (2013), had done a phenomenological study to explore Iranian mothers lived experiences of having a child with mental retardation (MR). Findings from this study contribute to a preliminary understanding of Iranian mothers’ experiences and needs. The results suggests introductory changes in nursing practice, staff education and program development to best serve mothers and their children with mental retardation. Gupta R, Kaur H, (2010), conducted a cross sectional study to examine the stress among parents of children with intellectual disability. 102 parents formed the sample of this study, 30 of whom had children without disability. Physical and mental stress are significantly correlated, gender differences in stress experienced occur only in the area of mental stress, and parents have higher mental stress score as compared to physical stress. Hidangmayum N, Khadi PB, (2012), conducted a study on parenting stress of normal and mentally challenged children. A differential research design was used to compare the level of parenting stress of normal and mentally challenged children. The study was carried out on a sample of 30 mentally challenged children and 60 normal children of age group 5-10 years. Abidin’s (1995) parenting stress index-short form was used to assess the level of
parenting stress. The results revealed that higher percent of parents of mentally challenged had clinically significant parenting stress (73.4%) than parents of the normal children (21.7%). Venkatesh Kumar G, (2008), investigated a psychological stress and coping strategies of the parents of mentally challenged children. The number of study samples was 62 parents of both father and mother with mental retardation child. The result revealed that the relationship between the psychological stress and coping strategies of the parents of mental retardation children was negative and highly significant.

Sivashanka P, Rangaswami K, (2009), conducted a study on psychological distress among mothers of disabled children, at Sweekaar Rehabilitation Institute for Mentally Handicapped, Secunderabad. The sample consists of 40 mothers of disabled children. The age range of children was 3 to 10 years. Tools used were Beck Depression Inventory (BDI), Depression, Anxiety, and Stress Scale (DASS). The findings of the study indicated that mothers with disabled children have significant anxiety, stress, and depression. Increased depression and anxiety level affected well-being of mothers of disabled children. The disabled children need effective rehabilitation training program and mothers of disabled children need counseling and effective psychological support to manage distress and to have better well-being.

Ergun Sibel, Ertem Gul, (2009), in Odemis, Izmir in Western Turkey conducted a study to determine the difficulties of mothers living with children suffering from intellectual disabilities, and the influence of socio-demographic factors aggravating the situation. It is evident that the parents, particularly the mothers, of physically or mentally handicapped children, experiences more stress than the parents of healthy children, and experience higher levels of anxiety.

Sachin S and Suresh V, (2014), noted a descriptive study to assess the burden among family caregivers of mentally ill clients at Gujarat. In non-probability convenient sampling method 60 family caregivers were identified with quantitative research approach. Caregiver’s burden scale with 30 items was used to collect the data from the family caregivers. The result revealed that 27 (45%) of family caregivers have mild burden, 8 (13.3%) of family caregivers have moderate burden, 9 (15%) of family caregivers have severe burden and 16 (26.7%) of family caregivers have expressed no burden at all.

Kerennappachu M.S and Godishala Sridevi, (2014), done a study regarding caregivers burden and perceived social support in mothers of children with mental retardation. 30 mothers with normal children were selected as control group and 30 mothers with mentally retarded children between 3 to 15 years of age were selected as experimental group. Caregivers burden scale (CBS) and Berlin social support scale (BSS) tools were used for collecting data. Mothers with mentally retarded children shown significant difference on caregiver’s burden than the mothers with normal children. Mothers with mentally retarded children were experiencing more burden.

Mukesh Morya, Atul Agarwal etal., (2007), examined to stress and coping strategies in families of mental retardation children at Rajasthan. They selected 50 parents as study samples and made them as two groups. First group 28 parents and they have children IQ more or equal to 50. Second group 22 parents with IQ less than 50 mental retardation children. Family interview for stress and coping in mental retardation (FISC-MR), NIMH-family efficacy scale (NIMH-FES), problem behavior check list were used to collect the data. The results were in families with mental retardation children with IQ less than 50 experienced significantly higher dality care stress, emotional and social stress and total perceived stress than the other group. Both groups used similar coping strategies. Having a female mental retardation child and nuclear family associated with higher stress in families.

Haneen To’meh, (2013), investigated a descriptive cross sectional study to assess the family burden among caregivers of mentally ill patients in Palestine. 50 caregivers of mental retardation, schizpphrenia, mood disorders were selected as convenient sampling method. Zarit burden interview, objective burden section from the Montgomery Borgatta caregiver burden scale was used to collect the data. The result showed that the mean of psychological, social, economic burden was low to moderate. The mean of objective burden was low (17.93). Taking care of mentally ill patients affects the family negatively. So nursing interventions should be focused on the need of the caregivers.

7. Review of literature related to effectiveness of educational package regarding care of mentally handicapped.

Hornby G, Singh NN, (2010), did behavioural group training with parents of mental retardation children. Seven parents of moderately mental retardation children were selected and pretest and posttest experimental design is used. Parents were taught to apply behavioral procedures to the specific problems presented by their children. Observations of parent child interaction in the home were made. Findings showed that the parents indicated that
the Programme was helpful and improved their knowledge, positive changes in parent child interaction at home also observed.

KumarSiandar et al. (2015), done a study on effectiveness of structured teaching Programme on knowledge regarding care of mentally retarded children among the caregivers in a selected special institution at Bhubaneswar, Odisha. Evaluative research approach with pre experimental descriptive design, pre and posttest without control group was used for this study. 34 parents and 16 caregivers for mentally handicapped were selected by convenience sampling method. The overall mean score in the pretest was 11.38 and 2.64 which is 37.93% of the total score. In posttest 52% of caregivers have excellent knowledge, 44%, good knowledge, and 4% had average knowledge. High significance difference was found between the pre test and post test scores. The result revealed that the structured teaching programme was effective.

CorenE, Rambotham K, Gschwandtner N, (2017), investigated to assess the effectiveness of parent training interventions for parents with intellectual disability to support parenting, parent child relations, safety parenting or family environment or to develop parenting skills. In quasi experimental design, randomized controlled trails used and 192 participants were involved. Standardized Cochrane method is used for 7 weeks to 12 months. Findings showed that some parents with intellectual disability are able to provide adequate parenting if they are given appropriate training and support to learn the parenting skills they need. There is a need for larger randomized controlled trails of parenting interventions with longer follow up.

SheenaBhatia and GeetaBhardwaj, (2017), conducted a study on effectiveness of planned teaching programme on knowledge regarding care of mentally retarded children among the care givers. The result shows that the planned teaching programme was effective in enhancing the knowledge of caregivers regarding care of mentally retarded children.

CONCLUSION
This review highlighted reviews on intellectual disability, perceptions of the caregivers towards the homecare of intellectual disability children and effectiveness of structured teaching module. The literature referred by the researcher were helpful for providing an insight into the various aspects of intellectual disability, care of intellectual disability children and their home care. They provided the framework for developing the conceptual framework and setting a suitable research design.

REFERENCES:
ARTICLES