STUDY OF BURDEN IN PARENTS OF CHILDREN WITH MENTAL RETARDATION

Kuldeep Singh*, Raj Kumar**, NovRattan Sharma*** and Dharmender Kumar Nehra****

ABSTRACT

Current research findings have indicated that diagnosis of mental retardation in a child is commonly experienced as having a devastating effect on parent’s lives. Parents or care-givers are definitely the heart of the family; who not only has to deal with the issues associated with child’s disability but also has to maintain the household. To date, a number of studies have demonstrated that caregivers are more vulnerable to develop mental and physical problems as compare to non-caregivers. The present study assessed and compared the family burden among the parents of children with mental retardation and healthy controls. Family Burden Interview Schedule was administered on 50 parents of children diagnosed with mental retardation (Department of Psychiatry) and 50 parents of healthy controls (Dental department) P.G.I.M.S. Rohtak. Statistical analysis was done using SPSS- 16.0. The results revealed a high prevalence of burden in study group. Further in comparison, a significant difference was found between study group and healthy control group. 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.

Keywords: Mental Retardation, Disability, Care-givers, and Family burden.

* Psychiatric Social Worker, Hisar, Email Kuldeep.olla@gmail.com
** Clinical Psychologist, Savera Drug De-Addiction Centre, Hisar.
*** Professor, Department of Psychology, M.D.U Rohtak.
**** Clinical Psychologist, State Institute of Mental Health, PGIMS Campus, Rohtak.
INTRODUCTION

Mental Retardation (MR) is defined as a disability characterized by remarkably low intellectual functioning (IQ < 70) in conjunction with significant limitations in adaptive functioning (American Association on Mental retardation, 2002). Worldwide prevalence of mental retardation is reported to be as high as 2.3% (Franklin & Mansuy, 2011), and in India it is reported to be around 2% for mild mental retardation and 0.5% for severe mental retardation (defined as IQ less than 50) (Srinath & Girimaji, 1999). In National Sample Survey of 2004, 94 people per 100,000 were found to be mentally retarded (National Sample Survey Organization, 2004). A series of factors are identified that can cause mental retardation but even though in at least 30 to 50 percent of cases, physicians are unable to determine etiology despite thorough evaluation (Armatas, 2009).

The fact that in addition to the core symptoms, children and adolescents with Intellectual disability often display a number of co-morbid behavioural problems, makes the situation more complex (Dykens, 2000; Einfeld, Piccinin, Mackinnon, 2006). Many researchers have concluded that the incidence of mental illness in persons with mental retardation is highest for persons classified as mildly or moderately mentally retarded (Jacobson, 1982; Iverson, & Fox, 1989). The liability associated with rearing such mentally handicapped children usually affects whole of atmosphere of home including routine family life, emotional aspects and financial resources of family (Kaur & Arora, 2010). Hence, for a parent, providing the high level of care required by a child with mental retardation may become taxing and may impact both physical and psychological health of caregivers.

Caregiver burden is defined as “a multidimensional response to physical, psychological, emotional, social and financial stressors usually associated with the experience of caring” (Kasuya, Polgar-Bailey, Takeuchi, 2000). Burden of care has two components namely subjective and objective burden (Hoeing & Hamilton, 1966). Objective burden includes measurable effects such as economic burden, caregivers’ loss of work, social and leisure activities, household disruptions such as child care, restrictions on relationships within and outside the family etc. Subjective burden is mainly the psychological sufferings of the caregivers themselves and is experienced by them such as depression, hatred, uncertainty, guilt, shame, embarrassment etc (Ravindranadan & Raju, 2007). Irrespective of the level of mental retardation; it is for sure that caregivers have to cope with their special needs and therefore disability in children are not only problem for affected children, but in real sense they are ‘family disease’ (Witt, Riley, Coiro, 2003). This seems more germane in our country where family bears the main burden of caring for such persons unlike in the developed world. Experts explain that in India families assume the role of primary caregivers for numbers of reasons (i) the Indian tradition of interdependence and concern for near and dear ones in

Vol. 8, No. 2, March, 2014
advantages and (ii) there is a paucity of trained mental health professionals required
to cater to the vast majority of the population; hence, the clinicians depend on
the family” (Avasthi, 2010).

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. While raising a
child with chronic condition, parents experience psychological stress and
disappointment when their child does not meet their hopes and expectations
(Barnett, Clements, Kaplan-Estrin, Fialka, 2003). Caring for those who are MR
is often itself stressful as care-giving affects several aspects of caregiver’s life
negatively including poor physical and emotional state (Pinquart & Sörensen, 2003;
Vitaliano, Zhang, & Scalan, 2003). Caregivers experience depression, burden, less
social support, and less coping resources than non-caregivers (Vitaliano et al.,
2002). As a general agreement, mental retardation can impose psychological
problems, social issues, and lifestyle restrictions that can affect quality of life of
the caregivers and family members, who also bear the considerable indirect costs
of patients’ disability. But this is only one side of the coin; there are examples
where act of caregiving is found to be associated with experiencing subjective
gains and satisfaction (Kulhara, Kate, Grover, Nehra,2012). Researchers concluded
that as youth’s symptoms improved, caregivers’ symptoms might also benefit
from reduced stress associated with a symptomatic child (Silverman, Kurtines,
Jaccard, & Pina, 2009; Carrion, Kletter, Weems, Berry, Rettger,2013). Its strong
impact, make it of extreme importance to investigate its mechanisms and find
new avenues towards its potential prevention and treatment for caregivers. It can
be assumed that the negative consequences of burden on caregivers may harm
their care giving effectiveness, whereas experiencing subjective gains and
satisfaction may enhance their caregiving ability. Hence present study is planned
to assess the degree of perceived burden among the parents of children diagnosed
with mental retardation and to compare them with normal controls in Indian setting.

METHOD

Sample

The data was collected from 50 parents of children diagnosed with mental
retardation and 50 parents of healthy controls. The place of the data collection
was the Department of Psychiatry and Dental Department P.G.I.M.S. Rohtak

Inclusion Criteria

- The parents who were living with the child with mental retardation
  (I.Q. below 70)
- The parents who were living with healthy children
- Age of child below 15years
- Either parent of the child (preferably mother).
Exclusion Criteria

- Any psychiatric illness in parents in both groups.

Tools Used

The following tools were used for the present study:

- **Socio-demographic Performa**: A special Performa designed for this study was used to gather socio-demographic details about the subjects.
- **Family burden interview schedule**: Family Burden Interview schedule developed by Pai and Kapur, 1981 was used to assess family burden.

This scale measures objective aspects of burden and it contains six general categories of burden, each having two to six individual items for further investigation. Subcategories include: Financial burden, Effects on family routine, Effects on family leisure, Effects on family interaction, Effects on physical health of family members and Effects on mental health of other family members.

Procedure

Total of 100 parents of children was assessed. 50 parents were recruited from the Dept. of Psychiatry and who had child diagnosed with mental retardation. Another 50 parents of healthy children were recruited from the Dental Department. Subjects fulfilling the inclusion criteria were selected for the study. A written informed consent was taken from them and the objectives and the procedures of the study were explained in detail.

RESULTS AND DISCUSSION

The study is exploratory in nature so the suitable statistical package for social science (SPSS: version 16.0) was used.

TABLE 1: Socio-demographic details of the study and control group

<table>
<thead>
<tr>
<th>Variable</th>
<th>Item</th>
<th>Study group</th>
<th>Control group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>(N=50) N (%)</td>
<td>(N=50) N (%)</td>
</tr>
<tr>
<td>Age</td>
<td>Mean± SD</td>
<td>34±7</td>
<td>30.92±3</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>8 (16%)</td>
<td>——</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>42(84%)</td>
<td>50(100%)</td>
</tr>
<tr>
<td>Residence</td>
<td>Urban</td>
<td>45(90%)</td>
<td>28(56%)</td>
</tr>
<tr>
<td></td>
<td>Rural</td>
<td>5(10%)</td>
<td>22(44%)</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married</td>
<td>50(100%)</td>
<td>50(100%)</td>
</tr>
<tr>
<td>Occupation</td>
<td>Unemployed</td>
<td>7(14%)</td>
<td>1(2%)</td>
</tr>
<tr>
<td></td>
<td>Housewife</td>
<td>40(80%)</td>
<td>43(86%)</td>
</tr>
<tr>
<td></td>
<td>Salaried</td>
<td>2(4%)</td>
<td>5(10%)</td>
</tr>
<tr>
<td></td>
<td>Business/self employment</td>
<td>1(2%)</td>
<td>1(2%)</td>
</tr>
<tr>
<td>Religion</td>
<td>Hindu</td>
<td>49(98%)</td>
<td>49(98%)</td>
</tr>
<tr>
<td></td>
<td>Sikh</td>
<td>1(2%)</td>
<td>1(2%)</td>
</tr>
</tbody>
</table>

Vol. 8, No. 2, March, 2014
Mental health professionals are the front line for treating team but role of caregivers cannot be ignored who continuously engaged in informal care of the sufferer. This informal care is the unpaid provision of care to a dependent person by family members or friends, has been considered the backbone of any long-term care system (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011). A caregiver provides physical and psychological support for a family member or friend, beyond what is typical of their relationship (Bridges, 1995). This has now been demonstrated that family members face financial problems, difficulty enjoying leisure activities, and various degree of distress while trying to understand the behaviour of patients living at home (Chieko, Shinji, Tomoko, Ryoji, Yasuo Fujii, Fumio, Toshinori 2002). It is well established that high degree of burden is associated with female, old age, low educational level, without employment and who are taking care of younger patients (Caqueourizar et al., 2006). The purpose of the present study was to compare family burden in parents of children with mental retardation (MR) and healthy controls. With a movement away from the institutional care and towards the home based care of persons with MR, it is the family that bears the brunt in caring for their disabled relative (Farber, 1959). A combination of factors appears to predict the likelihood of burden experienced.
by the caregiver. In present study parents in study group perceived high level of burden. This is corroborating with the findings of another study (Sethi, Bhargava, Dhiman, 2007). More specifically, mothers of children with MR displayed lower physical health, impairment in social relationships, in their psychological state and poorer perception of their environment. These findings are in accordance with previous studies, reporting parents of children with MR, particularly mothers, experience more burden than parents of typically developing children (Upadhyaya & Havalappanavar, 2008). When compared with normal controls, the experimental group experienced higher level of burden and the level of burden increased as the severity of MR increased. These findings are in keeping with those by the earlier investigators (Girolametto & Tannock, 1994). The possible reasons for this could be that a mothers spent more time with the children while caring for them; most mothers were home-makers without additional help and also were restricted to home with no time or provision for leisure activity (Beckman, 1983).

Involving caregivers in treatment may improve their attitude toward patients with psychiatric problem and, in doing so, enhance patients’ adherence and outcome (Sher, McGinn, Sirey, Meyers, 2005). Caregiving is generally considered as a cumbersome and difficult work. Although many families show a strong resilience in caring for an ill relative, their share of physical and emotional distress cannot be ignored (Swaroop, et al., 2013). It seems quite obvious that excessive burden negatively impact the caregiving process. Hence, family caregivers who provide care to other family members also need supervision or assistance in illness or disability (Medical Condition Dictionary, 2011). Present findings also highlight the importance of self-care for caregiver. Therefore, we advocate various tips suggested by experts that should be given to the care givers to balance their critically important care giving role with their own health and wellbeing (Sahoo, Brahma, Mohapatra, 2010).

**CONCLUSION**

Growing evidence suggests that care giving to these children leads burden to the caregivers that are the reason that prevailing stress or burden is reported by these individuals. Understanding how to manage the negative consequences of caregiving is critical to developing and implementing realistic, appropriate response strategies. There is no doubt that psychological evaluation and intervention programs should be considered as vital adjuncts to the management of MR; particularly among inaccessible segments of the population. The present findings have practical implications for assessing the health needs of caregivers who are taking responsibilities of a child with mental retardation or intellectual disability. In our country where we have limited resources and it is high time that we should realize that we may not develop holistic health of the patient if the caregivers are overburdened. So treatment providers should also shift their
Study of Burden in Parents of Children with Mental Retardation

focus to the mental health of care givers too along with that of individuals with MR. Having health caregivers can maximize the chances of MRs successful resettlement in society; it will be associated with increased met needs.

REFERENCES


