Burden of Care Perceived by the Principal Caregivers of Autistic Children and Adolescents Visiting Health Facilities in Lucknow City

Aparna Jain1, Naim Ahmed2, Pooja Mahour3, Vivek Agarwal4, Kanta Chandra5, Nitesh Kumar Shrivatav6
1Junior Resident, 2Associate Professor, Department of Community Medicine and Public Health, King George’s Medical University, 3Assistant Professor, Department of Psychiatry, King George’s Medical University, 4Professor, Department of Paediatrics, King George’s Medical University, 5Professor, Department of Physical Medicine and Rehabilitation, King George’s Medical University, Lucknow, Uttar Pradesh, India

Abstract

Background: Autism is extraordinarily difficult for families to cope with for various reasons. Perceived burden and care for the child with autism, available forms of social support, and the interactions between the autistic child and other family members are areas of significant concern for families. Objective: The objective of this study was to determine the burden of care perceived by the principal caregivers of autistic children or adolescent visiting health facilities in Lucknow city. Methods: The cross-sectional study was conducted from October 2016 to September 2017 with a sample of 90 principal caregivers (aged <60 years) of autistic children and adolescents aged 3–19 years and diagnosed with autism, attending government and private health facilities providing treatment for autism in Lucknow, Uttar Pradesh, India. Validated tools were used to assess the burden of care and disability level of autistic children. Data were analyzed using the software SPSS version 16. Results: The caregivers of autistic children and adolescents perceived the burden of care in different domains in varying extent with “caregiver’s routine” and “taking responsibility” domains affected the most. The burden perceived was found to be affected by the permanent residence of caregiver, rural/urban dwelling, type of family, socioeconomic status, age at which diagnosis was made, knowledge about autism and the severity of autism. Conclusions: Availability and easy accessibility of autism treatment facilities must be the most probable reason for less burden perceived in three domains, by caregivers of urban settings and those belonging to Lucknow. Furthermore, better knowledge on autism and family and friends’ support led to decrease in the burden perceived by the caregivers in various domains. Thus, it was found that the burden perceived can be reduced by universal availability of evidence-based early diagnosis and treatment of autism and improving the knowledge of caregivers about autism.

Key words: Autism, burden of care, caregivers of autistic children

INTRODUCTION

The burden has been defined by Platt (1985) as the presence of problems, difficulties or adverse events that affect the lives of psychiatric patients.[1] Any form of a chronic illness is a serious challenge, not only for the afflicted individual but also for the individual’s family.[2] Autism is extraordinarily difficult for families to cope with for various reasons.[3] Perceived burden and care for the child with autism, available forms of social support, and the interactions between the autistic child and other family members are areas of significant concern for families.[4]

The stress perceived by the caregivers has been found to be negatively correlated with low levels of several adaptive skills[5] and positively associated with the child problem behaviors,[6] female sex of the child and parents engaged in more lucrative and prestigious occupations.[7] Neither child diagnosis nor child daily living skill was found significantly related to parenting stress or mothers’ psychological distress.[8] Many parents reported receiving little support from their extended families in taking care of their child.[7]

Nagaraju and Wilson, in a study attempted to examine the burden and stress perceived by the mothers of autistic children, in which the author found that there was a significant association between burden and age of both the mother and
children. Burden increases as the child and mother get older. The study also revealed that stress was significantly associated with the size of family, age of the child, sex of the child, social support, and onset of the child’s illness.[9]

Uttar Pradesh a state in Northern India is the most populous country subdivision in the world, with dense population (820/km²) and 200 million inhabitants.[9] Lucknow, the capital of Uttar Pradesh, is the eleventh most populous city and the twelfth most populous urban agglomeration of India.[10] Being so highly populous, the health-care needs of this particular city becomes important. Autism is an upcoming health problem with increasing prevalence[11] but the online search suggests that its treatment is at its infancy in Northern India, especially in the Eastern parts of Uttar Pradesh. Parents of children with autistic disorder find themselves burdened with a lifelong responsibility of caring for their children and diminished attention to their own health.[11] Other than this, lack of knowledge about autism, lack of treatment, and if the treatment is available, it is unaffordable, adds on the stress.

In this context, the objective of this study was to determine the burden of care perceived by the principal caregivers of autistic children or adolescent visiting health facilities in Lucknow city.

**MATERIALS AND METHODS**

The present study was a cross-sectional study, conducted from October 2016 to September 2017, in child and adolescent psychiatry outpatient department at a tertiary care government center and four private centers for autism at Lucknow.

The study participants were principal caregivers (<60 years of age) of diagnosed children/adolescents with autism spectrum disorder, aged 3–19 years. Principal caregiver is the one who is continuously taking care of the autistic child/adolescent for the past 1-year (modified).[11] The duration of the study was 1-year. All the caregivers, visiting the centers, who qualified the selection criteria, were included in this study. Thus, a total of 90 principal caregivers of the autistic children and adolescents were included in the study.

Ethical clearance was taken from the institutional Ethical Committee of the King George’s Medical University UP, Lucknow, before commencing the study. Written permission was taken from the private centers included in the study. Written informed consent was taken from each selected participant to confirm willingness after explaining the survey purpose. Privacy and confidentiality of collected information were ensured throughout the process.

The burden assessment schedule was used to assess the burden on caregivers. This is an instrument developed by Thara et al., in 1998, at Schizophrenia Research Foundation, Chennai, to assess both objective and subjective burden experienced by the key relative or caregiver of chronic mentally ill patients using the process of stepwise ethnographic exploration.[11] Originally, the questionnaire was in English. Its validated Hindi translation was used in this study.[12]

It has a total of 38 items covering nine domains of the burden of care. One of the domains is “spouse related” consisting of 5 items. This domain is specifically used for mentally ill spouses; thus, this domain was excluded from the study. Hence, in the present study, 33 items (covering eight domains of the burden of care) were included. Each item was rated on a 3-point Likert scale. The responses were “not at all” (Score 1), “to some extent” (Score 2), or “very much” (Score 3) [Table 1].

Knowledge of the caregivers was also assessed regarding the diagnosis, core features, and treatment of autism. The details have been provided in an article published elsewhere.[13]

The children were assessed for the level of disability using the Indian Scale for Assessment of Autism (ISAA). ISAA consists of forty items rated on a 5-point scale ranging from 1 (never) to 5 (always). The 40 items of ISAA are divided into six domains – social relationship and reciprocity, emotional responsiveness, speech-language and communication, behavior patterns, sensory aspects, and cognitive component.[14] Further, the levels of disability are classified into no autism (score <70), mild autism (score 70–106), moderate autism (score 107–153), and severe autism (score >153).

Data were tabulated and analyzed using the software Statistical Package for the Social Sciences (SPSS) version 16 (IBM, New York, USA). The categorical variables were represented in the form of frequency tables. On applying the tests of normality, the data were found to be not normal. Thus, the median was used as the measure of central tendency for the continuous variables. Nonparametric test of significance such as Chi-square test, Mann–Whitney U-test, and Kruskal–Wallis tests was used for determining any difference between medians of two (or more than two) groups of a particular independent variable. \( P < 0.05 \) or \( P < 0.001 \) was taken as significant difference.

**RESULTS**

More than 50% of the caregivers experienced “to some extent” burden of care in the physical and mental health, external support, support of the patient, other relations, patient’s behavior, and caregiver’s strategy. While >70% of caregivers experienced “very

| Table 1: Scores of different domains and total adjusted score of the burden assessment schedule |
|-----------------------------------------------------------------------------------------------|
| **Domains**                                      | **Score (not at all)** | **Score (to some extent)** | **Score (very much)** |
|-------------------------------------------------|------------------------|----------------------------|-----------------------|
| Physical and mental health                      | ≤6                     | 7-12                       | 13-18                 |
| External support                                | ≤4                     | 5-8                        | 9-12                  |
| Caregiver’s routines                            | ≤4                     | 5-8                        | 9-12                  |
| Support of patient                              | ≤3                     | 4-6                        | 7-9                   |
| Taking responsibility                           | ≤4                     | 5-8                        | 9-12                  |
| Other relations                                 | ≤3                     | 4-6                        | 7-9                   |
| Patients behavior                               | ≤4                     | 5-8                        | 9-12                  |
| Caregiver’s strategy                            | ≤4                     | 5-8                        | 9-12                  |
| Total adjusted score                            | ≤33.3                  | 34.3-66.7                  | 67.7-100              |
much” burden of care in the “caregiver’s routine” and “taking responsibility” domains. Majority of the caregivers (64.4%) perceived very much total burden of care [Figure 1].

Significantly higher burden in the external support domain was perceived by the caregivers who belonged to districts other than Lucknow and caregivers belonging to nuclear families. In the caregiver’s routine domain significantly higher burden was perceived among caregivers who belonged to districts other than Lucknow. In the domain “support of patient,” the median score was significantly higher among caregivers belonging to lower middle class. Burden perceived was more in the “other relations” domain among caregivers belonging to nuclear families. The median score of the “patient’s behaviour” was found to be higher among caregivers belonging to rural areas and caregivers belonging to nuclear families. The median scores of different age groups of children, at which diagnosis of autism was made, were found statistically different in the “patient’s behaviour” domain and total burden of care. The burden of care was seen decreasing in all domains, as the age of diagnosis increased from <24 months to 49–72 months, followed by a sudden increase in burden in >73 months [Table 2].

Table 3 describes the domains of the burden of care in respect to knowledge of caregivers about certain aspects of autistic children. In the “patient’s behaviour” domain, the median scores of caregivers who “knew about their child’s problem,” who “knew about Autism” and who “Knew about the care modalities of Autism” were lower as compared to that of those who did not. Furthermore, the children were diagnosed for the severity of autism using ISAA. A positive correlation was observed between the severity of autism and total burden of care perceived by the caregivers.

**DISCUSSION**

The median total adjusted burden was 71.87 with an interquartile range of 63.28–77.08, thus depicting “very much” overall burden of care on principal caregivers. Similarly, overall “very much” burden was also perceived in two domains, “caregiver’s routine” and “taking responsibility,” thus depicting that among all domains of burden of care the caregivers perceived maximum burden in their personal routines (which include decreased time to look after their health, sleep disturbances, unable to relax, and satisfaction with patient looking after himself) and in the taking responsibility domain (which include caregiver meets patient’s financial needs, concern about future finances, sharing problems with others, caregiver responsible for all needs of patient). A recent study suggested that parents of autistic children themselves also have a greater prevalence of sleep problems than did parents of typically developing children.[15]

The median scores in the “external support” and “caregiver’s routine” domains were more (hence more burden) of the principal caregivers who belonged to districts other than Lucknow as compared to the caregivers who belonged to Lucknow. The caregivers from other districts lacked external support from family and friends more as compared to the caregivers from Lucknow. Furthermore, the caregivers from other districts were more dissatisfied with their personal routine than those who belonged to Lucknow. It depicts the importance of family support in caring a person with such lifelong problems. The total burden perceived was also more in the caregivers who belonged to districts other than Lucknow.

The principal caregivers who belonged to rural areas had more burden of care in the “patient’s behaviour” domain as compared to the caregivers who belonged to urban areas. The “patient’s behavior” domain includes “caregiver feels there is no solution, patient causes disturbances at home, patient’s unpredictable behavior and caregiver unable to take up a job.” The lack of proper health facilities in the rural areas could be a reason that the caregivers were unable to manage the patient’s behavior better as compared to the caregivers from urban areas. In a study, Harman stated that “social, cultural and economic factors played a significant role in the lived experiences of individuals with ASD and their families, and their ability to access appropriate diagnosis, treatment, and intervention.”[16]

The principal caregivers from nuclear families faced more burdens in the “external support,” “other relations,” and “patient’s behavior” domains. These caregivers’ relationship with friends and family was affected more than the caregivers who belonged to joint families. Thus, this finding depicts the need of family support in taking care of autistic children and adolescents. In addition, the patient’s behavior affected the caregivers from nuclear families more than the caregivers who belonged to joint families. The findings were different in a study by Nagaraju and Wilson, in which burden had no significant association with the family type. In the same study, the burden had no significant association with religion, the
Table 2: Comparison of medians of different domains of the burden assessment schedule with respect to the sociodemographic variables

| Sociodemographic factors | Physical and mental health | External support | Caregiver’s routine | Support of patient | Taking responsibility | Other relations | Patient’s behavior | Caregiver’s strategy | Total |
|--------------------------|----------------------------|-----------------|---------------------|-------------------|----------------------|---------------|-------------------|---------------------|-------|
| Religion                 |                            |                 |                     |                   |                      |               |                   |                     |       |
| Hindu                    | 12 (11-15)                 | 8 (7-10)        | 10 (9-11)           | 5 (4-6)           | 10 (8-11)            | 6 (5-7)       | 8 (6-10)          | 8* (8-9)            | 71.87 (63.54-76.30) |
| Muslim                   | 13 (11.75-15.25)           | 8 (6.75-8.25)   | 10 (8.75-11)        | 5.50 (5-6)        | 10 (8.75-11)         | 64.75-7.25    | 9 (6.75-10)       | 9* (8-10)           | 73.44 (66.41-78.65) |
| Sikh                     | 10.50 (9 -)                | 6 (-)           | 8 (7 -)             | 5.50 (5 -)        | 9 (8 -)              | 5 (-)         | 5.50 (4 -)        | 6.50* (6 -)         | 59.37 (56.25 -)     |
| Permanent residence      |                            |                 |                     |                   |                      |               |                   |                     |       |
| Lucknow                  | 12 (11-14)                 | 8* (7-9)        | 9* (8-10.75)        | 5 (5-6)           | 10 (8.25-11)         | 6 (5-7)       | 8 (6-10)          | 8 (7.25-9)          | 70.31* (62.5-75)    |
| Other district           | 13 (12-16)                 | 9* (7.75-10)    | 10.50* (9-11)       | 5 (4-6)           | 10 (8-11)            | 6 (5-8)       | 8.50 (7-10.25)    | 9 (8-10)            | 75* (67.71-79.43)   |
| Domicile                 |                            |                 |                     |                   |                      |               |                   |                     |       |
| Urban                    | 12 (11-15)                 | 8 (7-9)         | 10 (8.50-11)        | 5 (4.50-6)        | 10 (8-11)            | 6 (5-7)       | 8* (6-10)         | 8 (8-9)             | 70.83 (62.5-76.56)  |
| Rural                    | 13 (9.50-15)               | 8 (7-9)         | 10 (9-10.50)        | 5 (4.50-7)        | 10 (9-11)            | 6 (4.50-6)    | 10* (9-10.50)     | 10 (7.50-10.50)     | 72.92 (66.67-78.65) |
| Type of family           |                            |                 |                     |                   |                      |               |                   |                     |       |
| Nuclear                  | 12 (11-15)                 | 8* (8-10)       | 10 (9-11)           | 5 (4-6)           | 10 (8-11)            | 6* (5-7)      | 9* (7-10)         | 9 (8-10)            | 71.87* (66.67-78.12) |
| Joint                    | 12 (10-14)                 | 8* (7-9)        | 10 (8-10)           | 5 (5-6)           | 9 (8-11)             | 5* (4-7)      | 7* (6-10)         | 8 (8-9)             | 70.83* (59.37-75)   |
| Socioeconomic status**   |                            |                 |                     |                   |                      |               |                   |                     |       |
| Upper class              | 12 (11-14.75)              | 8 (9-7.95)      | 10 (8.25-11)        | 5* (4-6)          | 10 (8-11)            | 6 (5-7)       | 8 (6-9)           | 8 (8-9)             | 70.83 (62.76-75)    |
| Middle class             | 13 (11-16)                 | 8 (7-10)        | 10 (9-11)           | 6* (5-7)          | 10 (9-11)            | 6 (4-7)       | 10 (7-10)         | 9 (7-10)            | 75 (63.54-80.21)    |
| Lower class              | 10 (9 -)                   | 7 (6 -)         | 10 (7 -)            | 4* (4 -)          | 9 (8 -)              | 5 (3 -)       | 9 (6 -)           | 10 (7 -)            | 64.58 (56.25 -)     |
| Age at which diagnosis was made (months) |                 |                 |                     |                   |                      |               |                   |                     |       |
| <24                      | 13.00 (13.00-14.00)        | 8.00 (7.00-9.00)| 10.00 (9.00-11.00)| 5.00 (4.00-6.00) | 10.00 (9.00-11.00)  | 6.00 (5.00-7.00)| 10.00* (8.00-10.00)| 9.00 (8.00-10.00)   | 75.00* (71.87-79.17) |
| 25-48                    | 12.00 (11.00-15.00)        | 8.00 (7.00-10.00)| 10.00 (8.00-11.00)| 5.00 (4.00-6.00) | 10.00 (8.00-11.00)  | 6.00 (5.00-7.00)| 8.00* (6.00-10.00)| 8.00 (7.00-9.00)    | 70.83* (62.50-77.08) |
| 49-72                    | 11.00 (9.00-15.00)         | 7.50 (6.75-9.00)| 9.00 (7.75-10.00)  | 5.50 (5.00-6.00) | 10.00 (8.75-11.00)  | 5.50 (4.00-6.25)| 7.00* (6.75-9.25) | 8.00 (7.00-9.00)    | 67.71* (63.28-73.18) |
| >73                      | 13.00 (12.25-16.25)        | 8.00 (7.25-11.00)| 11.00 (10.00-12.00)| 6.00 (4.25-7.00) | 10.50 (9.25-11.00)  | 7.00 (6.00-7.75)| 9.00* (9.00-10.75)| 9.00 (8.00-10.75)   | 75.52* (73.44-84.37) |

*P<0.05, **Modified BG Prasad Scale Figures in parenthesis indicate interquartile range
These findings were replicated in the present study also. In the same study by Nagaraju and Wilson, the burden perceived by the caregivers was found negatively correlated with the social support. A similar finding was seen in the present study.

Among the caregivers who were interviewed, those who belonged to the upper class were found to have a lesser burden in “support of patient” domain as compared to the caregivers belonging to upper middle class and lower middle class. Similarly, caregivers who belonged to upper middle class had lesser median burden as compared to the caregivers belonging to lower middle class. Thus, a negative relationship was seen between socioeconomic status and the “support of patient” domain, i.e., as the socioeconomic status improved from lower middle class to upper class, the burden of care in “support of patient” domain decreased. A similar finding was seen in a study in which the annual family income and the burden perceived were negatively correlated.[8] Many families, due to their own socioeconomic status, are unable to access what few resources and services are available.[16] On the contrary, among the lower class, the burden perceived was found to be least in the “support of patient” domain. The most probable reason of this finding is that most of these caregivers were not providing treatment of any kind to their autistic children.

In the present study, the age at which child’s diagnosis was made affected all domains. The caregivers whose children were diagnosed as made as early as <24 months of age perceived the most burden in all the domains. The burden perceived was found to be decreasing as the age of diagnosis increased, but a sudden increase in the burden of care was seen in children who were diagnosed at >73 months of age. The difference seen was found statistically significant in the “patient’s behavior” domain. The needs of a child change once he/she crosses 72 months of age. This could be the most probable reason that the caregivers whose children were diagnosed after 72 months showed a sudden increase in burden in the “patient’s behavior” domain.[17]

The caregivers who had knowledge about autism had a lesser burden in the “patient’s behavior” domain. Thus, depicting that knowledge about the problem had helped the caregivers in handling the “patient’s behavior” in a better way. The knowledge helped the caregiver in coping with the feeling of “no solution,” also in handling the child’s unpredictable behavior and the disturbances caused by the child at home. One another finding was that the caregivers who knew about their child’s problem were able to formulate a better “caregiver’s strategy.” A mere knowledge of the name of their child’s problem led them to gain more support from friends. They compensated their child’s shortcomings. They could better understand the day-to-day stress faced by their child and thus did not think that they were the only one who was trying to improve the child’s situation, thus did not want a temporary separation from the child. “Things are not moving quickly

### Table 3: Comparison of median scores of different domains of the burden assessment schedule with respect to the “knowledge about autism” of principal caregiver

| Knowledge of caregivers | Physical and mental health | Support of patient |
|-------------------------|----------------------------|-------------------|
|                         | External support            | Caregiver’s routine | Taking responsibility | Other relations | Caregiver’s strategy |
|                         | Taking responsibility       | Caregiver’s strategy | Other relations      | Caregiver’s strategy |
| Knowledge about autism  | Yes                        | 12.00 (11.00-15.00) | 8.00 (7.00-10.00) | 10.00 (9.00-11.00) | 5.00 (5.00-6.00) | 10.00 (8.00-11.00) | 6.00 (5.00-7.00) | 8.00* (6.00-10.00) | 9.00* (7.00-9.00) | 7.83 (6.32-9.00) | 7.83 (6.32-7.96) | 7.83 (6.32-7.96) | 7.83 (6.32-7.96) |
| Knowledge about autism  | No                         | 13.00 (10.50-16.00) | 8.00 (7.00-9.00) | 10.00 (9.00-11.00) | 5.00 (5.00-6.25) | 10.00 (8.00-11.00) | 6.00 (4.00-7.50) | 9.00* (7.00-10.00) | 9.00* (7.00-10.00) | 7.83 (6.32-9.00) | 7.83 (6.32-9.00) | 7.83 (6.32-9.00) | 7.83 (6.32-9.00) |
| Knowledge about the treatment of Autism | Yes | 12.00 (11.00-15.00) | 8.00 (7.00-10.00) | 10.00 (9.00-11.00) | 5.00 (5.00-6.00) | 10.00 (8.00-11.00) | 6.00 (4.00-7.50) | 9.00* (7.00-10.00) | 9.00* (7.00-10.00) | 7.83 (6.32-9.00) | 7.83 (6.32-9.00) | 7.83 (6.32-9.00) | 7.83 (6.32-9.00) |
| Knowledge about the treatment of Autism | No | 12.50 (10.00-16.00) | 8.00 (7.00-9.00) | 10.00 (9.00-11.00) | 5.00 (5.00-6.25) | 10.00 (8.00-11.00) | 6.00 (4.00-7.50) | 9.00* (7.00-10.00) | 9.00* (7.00-10.00) | 7.83 (6.32-9.00) | 7.83 (6.32-9.00) | 7.83 (6.32-9.00) | 7.83 (6.32-9.00) |

Figures in parenthesis indicate interquartile range
enough for families who are living with the uncertainty of not knowing what condition their children have. The lack of awareness negatively impacts the likelihood that families will fully understand their children’s ASD, much less seek appropriate intervention.\textsuperscript{16}

In a study, the burden was positively correlated with the caregiver’s age, child’s age, number of children, and age of onset of illness while negatively correlated with the educational status of caregiver.\textsuperscript{8} The similar findings could not be replicated in the present study.

Thus, the caregivers of autistic children perceive “very much” burden of care. The availability and easy accessibility of autism treatment facilities must be the most probable reason for less burden perceived in three domains, by caregivers of urban settings and those belonging to Lucknow. This will improve early diagnosis as well. Better knowledge on autism led to decrease in burden perceived in the patient behavior and caregiver’s strategy domains. Family and friends’ support is necessary in improving the burden perceived by the caregivers in various domains. The burden perceived by the caregivers can be reduced by universal availability of evidence-based early diagnosis and treatment of autism, improving the knowledge of caregivers about autism and support of family and friends.

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There are no conflicts of interest.

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