Perception of Families of Children with Specific Learning Disorder: An Exploratory Study

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ABSTRACT

Background: Parents have a tremendous influence on their children’s academic and social success. Unfortunately, a majority of them do not have a concrete idea on how to assist their children, impacting negatively on both the parents and the child. Currently, there is sparse research on parents’ experiences in dealing with children with specific learning disorders (SLD). The current study was planned to explore the perception of families of children with SLD. Materials and Methods: Five focus group discussions (FGDs) including 30 parents of children with SLD aged between 8 and 14 years were carried out. Each group composed of five - seven participants. A format to guide FGDs was made to bring uniformity across groups. The transcripts were analyzed using the content analysis method to extract key conceptual themes. Results: The parents showed lack of conceptual knowledge with regard to the SLD symptomatology as well as proper guidelines to deal with their child’s problem. They displayed negative attitudes and reactions toward their child’s diagnosis of SLD, such as rejection, denial, over-protection, and loss of hope. Their caregiving was also perceived to place physical, personal, social, financial, and emotional burden by the majority of parents. Conclusion: The study highlights the experiences of parents dealing with SLD in terms of their inadequate knowledge, adaptational difficulties, and burden. The findings also reiterate the need to focus on family perspective and experiences when working with a learning-disabled child. Various supportive strategies are required to empower families, which would help alleviate their burden. Moreover, parents’ training to strengthen child’s learning skills is also warranted.

Key words: Burden, families, perception, specific learning disorder

INTRODUCTION

Parents are the primary caregiver for a child and have a great potential to support and advance their child’s academic success. A strain-free and supportive home environment can positively regulate the learning behavior of a child with specific learning disorders (SLD). Researchers have also advocated about educational treatment of SLD that involved familial contexts and needs. Unfortunately, parents have inadequate knowledge and information of SLD, leading to lack of or delay in recognition of...
this hidden disorder. They do not realize that there is a need for some immediate action and attribute it to developmental process. Therefore, parents deny learning problems in their children when teachers or others try to point them out.\textsuperscript{[2]} If the child is diagnosed with a disability, parents generally display negative attitude toward the problem, including denial, rejection, and self-blame.\textsuperscript{[3,4]} They get disappointed and display hostility or over-protectiveness toward the child’s problem, failing to make realistic demands from the child.\textsuperscript{[5]} Therefore, repeated failure or poor performance despite continuous efforts and practice can negatively impact parents and predispose them to higher levels of stress, frustration, and dissatisfaction.\textsuperscript{[6]} It may extend to various dimensions, including personal discomfort, financial crises, and lower quality of life.\textsuperscript{[7-9]}

Therefore, for an effective remedial training program, it is important to have an in-depth understanding of the parents’ perception and experiences regarding a child with SLD. A holistic management can be planned based on the needs of both children with SLD and their parents. However, there is a paucity of studies in the Indian context that have focused on the experiences of the parents of children with SLD. Hence, the present study was planned to explore the parents’ knowledge of the SLD, their attitude/reactions toward the child’s learning disorder and the impact of child’s condition on them.

**MATERIALS AND METHODS**

**Study design**
A descriptive qualitative study approach was adopted to gain in-depth understanding and insight about family’s perceptions and experiences regarding SLD.

**Participants**
Thirty parents of children with SLD participated in five focus group discussions (FGDs). All children were diagnosed as cases of SLD by consultant psychiatrists. Further psychoeducational evaluation was done using Specific Learning Disorder: Comprehensive Battery\textsuperscript{[10]} to identify the type of learning disorder in specific academic areas. The families were selected from three centers in Delhi, India: a premier tertiary care hospital (Department of Psychiatry, All India Institute of Medical Sciences) and two non-government learning centers. Parents with ages between 27 and 45 years, educated at least till 10\textsuperscript{th} standard, staying with the learning-disabled child, seeking treatment for their child’s (aged 8–14 years) learning problem and willing to give a written informed consent were approached and included in the study. Participants were excluded if another family member or sibling of the child also had psychiatric, neurological, or chronic medical illness or if they refused to give informed consent for the study. Additionally, parents of learning-disabled children with comorbid psychiatric condition, except for attention deficit hyperactivity disorder (ADHD, assessed on MINI-KID)\textsuperscript{[11]} or a known history of organic conditions such as major neurological or medical disorders or impairment in hearing, vision, or speech due to which learning difficulties could occur were excluded from the study.

**Measures**

**Sociodemographic data sheet:** A semi-structured interview schedule for the parents was prepared for the study. It included sociodemographic details of parents along with the details of past or current history of physical and psychological problems of parents.

**FGD format guide:** A format was prepared to guide FGDs designed for the study to gather information on specific concerns of parents. This discussion method encouraged participants to discuss their experiences, concerns, and difficulties, facilitating an understanding of their perceived burden in a specific context.

**Ethical consideration**
Ethical approval to conduct the study was obtained from the institutional ethics committee. A written consent was collected from all parents prior to participating in the study.

**Procedure**
All screened parents were explained about the nature and purpose of the study and were assured of complete confidentiality. After obtaining the participants’ informed written consent, FGDs were conducted [Figure 1]. Each FGD composed of five–seven participants. The FGDs began with open-ended questions and were continued till saturation of themes (i.e., 45–120 min). Each session was audio-recorded along with note tracking of FGDs. Recordings obtained...
from FGDs were transcribed verbatim after the removal of all personally identifiable information.

**Analysis**

Qualitative data generated through FGDs were subjected to content analysis. For this, the manuscripts were analyzed manually. The themes of discussion were identified and coded according to the objectives and pre-determined topics or categories. Additionally, some other newer themes were also identified. The codes were then analyzed according to the categories for frequency of repeated patterns across all the manuscripts. To enhance objectivity of the coding and to reduce biased decision in category development, the identified codes were cross-checked by three other investigators (investigator triangulation method). Thus, the coding agreement was achieved as 95%.

**RESULTS**

Thirty parents took part in the five FGDs. The mean number of participants in each group was 6 (ranged 5–7). The mean age of parents was 38.4 (SD = 3.8) years along with 14.3 (SD = 2.1) years of formal education. A majority of the participants were mothers (60%, n = 18), currently housewife (66.7%, n = 20), and living in nuclear families (63.3%, n = 19). All participants belonged to middle socioeconomic status and were from urban locality (100%). The mean age of their children was 10 years (SD = 1.7) and all had SLD-mixed type. Four children (13.3%) had the signs of ADHD or attention-deficit disorder and out of them only one child was on medication (3.3%).

Parents discussed their experiences related to learning problems of their children. Major themes and sub-themes were identified [Table 1].

| Themes                        | Sub-themes                      |
|-------------------------------|---------------------------------|
| Lack of information           | Poor knowledge                  |
|                               | Delayed identification          |
|                               | Lack of guidance                |
| Attitude toward diagnosis     | Denial                          |
|                               | Rejection                       |
|                               | Over-involvement and loss of hope|
| Burden perceived by parents   | Physical                        |
|                               | Personal                        |
|                               | Social                          |
|                               | Financial                       |
|                               | Emotional                       |

Table 1: Major themes and sub-themes identified after content analysis

**Poor knowledge**

Twenty-nine parents reported that they did not have good knowledge about SLD. They were unable to recognize the signs of SLD in the early years of childhood and even at the time of SLD diagnosis. Majority of them had heard the word “SLD” either during the FGD for the first time or a few months back. Parents also admitted that before the diagnosis of SLD, they thought that the behavior and attitude of their child was responsible for their poor academic performance and believed that the child’s academic performance will improve either with the maturity of the child and/or by a reduction of their problem behaviors (n = 11).

**Delayed identification**

All parents disclosed that they noticed learning difficulties in the child during nursery class but identified it as illness after a long time. As a consequence, SLD got diagnosed in either third or fourth class or after the symptoms had been present for 2–3 years, that is, the child was 10 years of age. Twenty-seven parents agreed to delayed identification of SLD diagnosis.

**Lack of guidance**

Participants informed that they did not get proper guidance to gain information about SLD or to learn strategies to deal with it. They explored about the child’s learning problem either by themselves or through a Bollywood Movie “Taare Zameen Pe- Stars on the Earth” (n = 20). A few parents learned about SLD from other parents or their relatives (n = 5). Parents disclosed that teachers and counselors did not guide them for further management of the child’s learning problem and only informed them about the child’s behavior and poor academic performance (n = 24).

**Theme 2 – Attitude toward diagnosis**

Parents disclosed their reactions toward the child’s diagnosis of SLD [Table 3]. Negative attitudes were expressed by parents toward learning issues as detailed below:

**Denial**

At the initial phase of SLD diagnosis, most of the parents were in a denial state (n = 9). They did not consider poor academic performance as a learning disorder. They were resistant to the diagnosis itself and blamed others for the problem, namely school system, uncooperative teacher, vast curriculum, child’s behavior problem, etc. Some parents were not even ready to get their child’s psychoeducational assessment done.
Rejection
A substantial number of parents accepted that they were initially ignorant about the nature of the problem in their child \( n = 17 \). In other words, acceptance of the problem was difficult for the parents and other family members, and because of that, they took more time in adjusting to the reality.

Over-involvement and loss of hope
Some parents acknowledged the SLD diagnosis and worked hard to help their child \( n = 7 \). Some parents quit their jobs to promote their child’s interest and learning \( n = 3 \). They started investing a lot of personal time to train the child but did not get favorable results. Due to that, sometimes, parents lost hope about the child’s future and questioned the child’s overall development and vocational career.

Theme 3 – Burden perceived by the parents
Results demonstrated that the presence of a learning-disabled child in the family led to following parental burden [Table 4]:

Physical burden
Twenty-six mothers highlighted issues related to physical health and burden. They had to spend extra hours for the child than what is usually required to complete their homework and schoolwork. All parents complained of common physical health issues that included exhaustion, fatigue, and poor quality and lack of sleep.

Personal burden
Personal burden from investing more time in the child’s learning concerns was expressed by all the parents. All
mothers indicated that they spent long hours daily in helping their child in academics, while the fathers usually remained busy or were out of the city for their jobs. Hence, the parents themselves could not spend quality time together. Additionally, most parents expected spousal support and empathy, but many of them did not find their spouses to be supportive or helpful in the child’s academic care. Consequently, mothers became irritated and disheartened, which led to quarrels among parents, discipline-related disagreements, and marital conflicts.

Social burden
Nearly all parents indicated that to some extent, the child’s academic problem also affected their own social life. Parents indulged explicitly in the child’s academic activities, due to which they were unable to take out time for their social life. Parents said that they had to put aside their leisure activities, families, and social gatherings that they enjoyed before the child’s illness.

Financial burden
Seventeen parents reported that the child’s academic difficulties increased expenditures in the family. They were seeking help from tutors or special educators at home or at private learning centers, which was an additional expense. Eight parents highlighted that they still did not see much improvement in the child’s learning, yet they continued with the same because they did not have any idea about how to manage on their own.

Emotional burden
Half of the parents reported that they started to think and perceive things more negatively, lost their interest in leisure activities, and became more anxious. Parents generally concealed their negative emotions instead of expressing them. However, sometimes, they felt frustrated and lost their temper if the child did not grasp things easily. Almost all parents expressed concern about the child’s future.

**DISCUSSION**
To the best of our knowledge, this is one of the first studies from the Indian subcontinent to explore the parent’s experiences in rearing a child with SLD. Even globally, relatively few exploratory studies have focused on perceptions of families of children with learning disability.[12,13] The findings emerging from the current study indicate that parents had limited knowledge of the illness, negative attitude toward the illness, and felt burdened from care of these children.

**Lack of information**
The greatest problem faced by the parents was the lack of information about SLD. Despite being highly educated and belonging to economically well-off families, parents had insufficient knowledge about the core basic issues of SLD.[7] As observed in other developmental disorders.[14] Due to their limited knowledge about SLD, parents were not fully cognizant of the learning and behavioral problems manifested by the child at home and school. They had mistakenly labeled SLD as the child’s behavior, attitude and concentration-related problems, thereby not warranting immediate action. This finding has an agreement with the previous study where the majority of parents could not correctly explain the term “SLD” and were not aware of its etiology.[7] Another study reported that parents described SLD as “difficulties or problematic

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Table 4: Burden perceived by parents (Theme 3)

| Themes                     | Sub-themes                              | Participants | Excerpts                                                                                                                                                                                                 |
|----------------------------|-----------------------------------------|--------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Burden perceived by parents| Physical                                | 26           | “I spend endless hours and put greater effort into my child’s academic success by helping him to complete his homework and to prepare him for examinations. Due to this, I frequently experience physical tiredness” |
|                            | Exhaustion, fatigue, poor quality, and lack of sleep | 30           | “He is unable to complete his work if I don’t sit with him. I give extra time to his school work”                                                                                                           |
|                            | Personal                                | 30           | “Because of child’s academic problem, I made drastic changes in my routine. As a result, I wasn’t able to steal some time for myself, my younger child and my family” My husband is not able to understand the learning problems of our child, which creates a lot of problem between us” |
|                            | Quarrels among parents, discipline-related disagreements and marital conflicts | 26           | “As I spend a lot of time teaching him, we are neither able to follow our hobbies, neither spend much time with our family members like we were doing previously” “We feel that instead of going outside or attending a function, we should use that time to teach our child” |
|                            | Social                                  | 30           | “Our family is well educated. Everyone has good vocational and professional profile. What will happen to him, if he does not improve or learn properly? This thought has always bothered me” |
|                            | Affected social life                     | 15           | “Due to child’s poor academic performance, my wife started having headaches and depression”                                                                                                           |
|                            | Social restrictions                      | 17           | “The fee for tuition and special educators is very expensive. They charged 4000-7000 INR or more for 4-5 classes which we can’t afford”                                                                 |
|                            | Reduced social network                   |              | “Expensive management services”                                                                                                                                                                         |
|                            | Financial                                |              | “Emotional burden”                                                                                                                                                                                      |
|                            | Emotional                                |              | “More anxious, Thinking and seeing things negatively, Concern about children’s future”                                                                                                                   |
The parents reported that they identified the child’s learning difficulties at the level of nursery itself. However, they misconceived it due to their poor awareness about the illness. They acknowledged it as an illness after 2–3 years of occurrence or mostly, when he/she was 10 year of age. Parents never sought help for early assessment from mental health professionals, resulting delay in interventions for these children. The mean delay in SLD diagnosis was found to be 5.8 years in 2007 and 3.4 years in 2014. If, somehow, the parents recognized the child’s learning difficulty, they did not get adequate guidance from schools or others. They explored the child’s learning problem either by themselves or from other sources such as movies, other parents, or relatives. A study also documented that parents had limited sources of information to know about the illness and only 3 parents out of 25 pairs of parents acquired knowledge about the illness from psychiatrists and mental health nurses. Studies had also reported that parents noticed learning-related problems in their children at the initial period, but they were unclear about how to care for these children and where to seek help. Parents of children with SLD had consulted teachers, neighbors, relatives, other parents, allopathic practitioners, and traditional healers before reaching a clinical psychologist and special educators.

Attitude toward the diagnosis
Specific features of learning disabilities are usually benign in nature which leads to delayed diagnosis and intervention. Moreover, it may produce intolerance in family toward the diagnosis. Negative attitudes or responses such as denial, rejection, loss of hope, and over-involvement were important themes that emerged in the group discussions. Findings of discussions indicated that most of the families took more time to accept the child’s diagnosis. In most cases, the parents were initially ignorant about the child’s learning problem, that is, denial and rejection as similar to those related to bereavement and later on, they started bargaining to themselves for the acceptance of the diagnosis. Furthermore, some parents accepted the diagnosis and treatment of the child’s learning problem and worked very hard to improve the child’s learning skills. Undoubtedly, they failed to make realistic expectations, leading to frustration and confusion. A study had reported that after the acceptance of diagnosis, parents showed excessive involvement (e.g., more time and energy) in the child’s homework and learning, which increased parents’ frustration, whereas in another study, some parents lost hope that the child will improve at all in future and attain higher education and adequate professional career.

Burden perceived by parents
In this study, parents experienced various types of burden during the caregiving of their child with SLD. Early studies also documented different types of difficult life situations that parents encounter in caring for these children. Parents were physically drained from investing time and energy on numerous methods to improve their child’s academic performance. They neglected their own comfort and the care of other family members and restricted their family and social life, such as regular family activities and hobbies and meeting with friends, relatives, or extended families. When parents failed repeatedly to manage the child’s concentration on homework and problematic behaviors and received frequent complaints from school teachers, they would get disappointed and would give up at times. Moreover, the child’s condition predisposed parents to higher levels of stress, frustration, and dissatisfaction and it often created disturbances in the relationship between the parents and the child. Parents commonly experienced more psychosomatic and emotional disturbances than those parents who had children with normal development. These parents experience mild level of anxiety and lower quality of life. Studies have categorically highlighted parents’ common anxieties and worries, which are mainly associated with the child’s chronic poor school performance and future prospects in life, along with the parents’ visits to the clinics for child’s treatment.

Awareness about SLD, harmonious familial relationships, and available resources and guidance are crucial factors in facilitating child care and mitigating parental stress. One study identified that along with information needs, the psychological, emotional, and instrumental supports play a significant role in reducing the tension and anxiety of these caregivers. Therefore, to enhance the caregivers’ psychosocial well-being, in-depth family education about SLD, remedial program, and parenting techniques for behavioral problems should be provided by mental health professionals. This can be promoted by upgrading the parents’ knowledge about the illness, developing caregiving skills, and enhancing social support available within the family, schools, and the community.

The strength of the index study includes assessing, for the first time, the perception of families of children.
with SLD from the Indian subcontinent. Findings of the index study will help understand the perspectives of the parents, which can reduce the child’s learning problem and caregiving burden. However, there are some confounding factors that could influence the study findings to some extent, such as ambitions parents, a lengthy procedure of assessment and diagnosis of SLD, limited manpower and resources, and lack of parent support groups. In our study, some parents were found more ambitious about their child’s academic success. When they come to know about the child’s learning problem, they became discouraged and started experiencing frustration and sorrow. During FGDs, these parents expressed their disappointment explicitly as compared with other parents who had not expected more from their child. It was also found that parents faced difficulties during assessment procedure of SLD where they spent months rushing to a government hospital to avail of the benefits of certificates, worsening their experience and burden. Another important factor could be the disproportionate teacher—student ratio at schools and limited workforces such as school counselors, remedial teachers, and professionals who cannot give frequent one-to-one attention to the child’s learning problem due to the load of their regular work. Because of that, parents might feeling incompetent to support their children, which further aggravates their caregiving burden. Additionally, in India, there is lack of parent support groups. Due to this, parents did not receive sufficient emotional support and practical advice and information as well, worsening their experiences.

CONCLUSION

To summarize, parents had limited knowledge about SLD, thereby failing to express a positive attitude toward the SLD diagnosis. Additionally, severe compromises in daily routines of parents in order to invest of time and energy for the child further add to caregiver’s burden. The results add crucial points to the existing literature. However, much work is required with a more sophisticated study with SLD from the Indian subcontinent. Findings of their children, which further aggravates their caregiving burden. Additionally, in India, there is lack of parent support groups. Due to this, parents did not receive sufficient emotional support and practical advice and information as well, worsening their experiences.

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Conflicts of interest
There are no conflicts of interest.

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