

Experiences of Parents with Children Having Learning Disabilities and/or ADHD in Pakistan

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ABSTRACT: This interpretive phenomenological qualitative research study explored the psychological and emotional experiences of parents with children having specific learning disabilities in Pakistan. Focus group discussions with five parents were conducted on Zoom. After the data collection from each of the participants was assessed, a cross-case analysis of the data was completed to develop a list of the themes common among the participants. The sub-themes and the themes originated from the codes are: (1) Parents' Challenges, with the sub-themes of Parenting Style, Emotional Responses and Sufferings; and (2) Support from Academia with the sub-themes of Relationship with the teachers, Financial Stress and Modifications in Assessments/ Examinations. The themes originated after the focus group discussion with the five parents contain the struggle of the parents of LD children in preparing them to do better academically and socially. The findings revealed that parents of children with learning disabilities have a very challenging and demanding role. Their struggles and challenges are more exhausting emotionally, physically, and financially. Parents struggle to identify academic problems faced by children due to lack of awareness, which adds to their struggle as well as the children. Parents are the primary caretakers and guardians and are responsible for the upbringing of their children. It is not easy being a parent, but the situation gets difficult when children are identified with learning disabilities.

KEYWORDS: learning disabilities, parents, emotional trauma, financial stress

1. Introduction

According to the National Joint Committee on Learning Disabilities (Jones and Wallace 2013), an organization working for the welfare and education of learning disabilities (LD) since 1975, learning difficulties are a heterogeneous group of disorders that include difficulties in reading, writing, listening, speaking, comprehension and mathematical abilities (Waqar and Vazir 2010). They are caused due to some malfunctioning of the central nervous system and can affect the entire life, although it has been observed that many times learning disability students do not exhibit any dysfunction of the brain. Upon reflecting on the above definition, it is evident that it is not one disorder but a group of disorders that affect the learning abilities of specific children (Waqar and Vazir 2010). Therefore, it is not likely that all LD students show the same level of disability. In a classroom with five LD students, each will be exhibiting a different disability with varying severity ranging from borderline to severe. It can be said that learning disabilities are not like other medical problems with known causes and symptoms. Rather, LD is an extensive term that encompasses a variety of causes, symptoms, supervisions, and actions. The marks of a learning disability on a child's life can be extremely distressing (Mishna 2003). Parents with children having learning disabilities have a very challenging and demanding role as a parent. Their struggles and challenges are more exhausting emotionally, physically, and financially. Parents struggle to identify academic problems faced by children due to lack of awareness which adds to their struggle as well as the children. Parents are the primary caretakers and guardians and are responsible for the upbringing of their children. It is not easy being a parent, but the situation gets difficult when children are identified with learning disabilities (Mearig 1992).

As opposed to the developed countries, the educational institutions of Pakistan, a country which is still in the process of developing, are still not ready to give students with learning disabilities a fair chance to grow and be useful members of society (The Express Tribune 2013).

This is because of a lack of awareness and knowledge about learning disorders. Pakistan is a country where the population ratio of rural vs. urban is 60 % and 40% respectively. It is not only in rural areas that people are unaware of the learning disabilities in their children, much of the urban population as well is still unaware of it; some go into the denial phase when told that their son/daughter must be diagnosed by a psychologist. According to the chief executive of the Foundation for Rehabilitation and Education of Special Children, Ms. Ashba Kamran, 10 to 18% of children in Pakistan's private schools have been diagnosed with learning disabilities whereas the situation is even graver in the public sector schools (The Express Tribune 2013).

1.1. Challenges faced by parents of LD children

There is no doubt that the family, especially the parents play an important role in the education of their LD child. From the first stage of detection till the identification and diagnosis, parents face a lot of challenges at every stage. They mostly complain about the school's administration's biased attitude towards the parents of non-LD children (Bdour, Beirat and Al-Bustanji 2019). In contrast to teachers who mainly focus on the academics of their pupils, parents of LD children give equal importance to social development, as well as they want their child to enjoy the learning process (Gasteiger-Klicpera, Gebhardt and Schwab 2012). Most of the parents complain about the lack of communication between the teachers and themselves. They held teachers responsible for having a negative attitude towards their LD child and considered the parents as having low social and cognitive abilities due to their child's disability. Moreover, as the schools are more concerned about their reputation as compared to imparting knowledge or putting more effort into their students, therefore, the most affected ones are the LD students. Due to the limited involvement of parents of LD children, these children suffer more academically (Alobaid 2018).

1.2. Research question

This paper focuses on the experiences of parents with children having a specific learning disability in Pakistan. The primary research question is: *What are the experiences of parents having children with a specific learning disability in Pakistan?*

2. Literature Review

Learning disability refers to delays or deviations and discrepancies in performances in subjects like arithmetic, reading, and writing. A child with a learning disability is not subjected to mental retardation. (Harris, Swanson and Graham 2003). Some of the common factors leading to learning difficulties include genetic factors or neurobiological disorders that alter the functioning of the brain. This change in the way your brain functions affects the cognitive processes related to learning such as reading, writing, or sometimes math (Thomas and Woods 2006). Parents are the primary caretakers and guardians and are responsible for the upbringing of their children. It is not easy being a parent, but the situation gets difficult when children are identified with learning disabilities (Mearig.JS 1992). The journey is not only emotionally and financially tiring but is challenging and exhausting. The entire experience is not only difficult and painful for the child, but also the parent who sometimes is unaware of their children's learning disability (ong 2001). Parents often do not realize the gap in learning faced by their children till they reach school-going age. Lack of support from the community and schools results in great emotional trauma for the parents and children alike (Ow 2004).

The initial response of the parents is usually seen to be negative and denial. Parents often go into a depressive phase where they keep questioning why this has happened to them and this sometimes goes on for years and years (Pain 1990). Blaming is also another way parents try to cope with the painful truth. Both parents blame each other for their child's learning disability (Polambo 1995). In most cultures, mothers are usually labeled for being responsible for their child's disability. Some parents also consider their child's learning disability as a curse. The

emotional well-being of these parents is negatively affected as they find themselves overwhelmed with the day-to-day challenges and struggles that go into raising children with learning disabilities. Parents experience guilt as they blame themselves or each other for their child's LD which sometimes also causes marital problems (O. Smith 2001).

Parents want their children to excel in all aspects of life including social, academic, and family life. When children face obstacles to flourish in these aspects parents sometimes struggle to identify the root cause of this delay in their performance. The discovery of a learning disability in a child is devastating and frustrating for the parents as they have little or no knowledge of how to help their child (O. Smith 2001). Parents often see learning disabilities as abnormalities and feel ashamed of discussing them with others (Spratt 2007). Family support plays a vital role in the positive upbringing of children with learning disabilities. Mothers have often complained of being blamed for their child's learning disability and therefore they refrain from seeking support or sometimes even stop perusing help for their child. The constant comparison of children with LDs with those without these LDs of the same family members causes the parents to isolate and detach from their children (Scroufle 1977). Parents of children with learning disabilities are reportedly more stressed due to the challenging experience of providing care to their children which include health issues, emotional, greater feelings of restriction, and higher levels of parental depression. The impact is also observed on their financial abilities as it has become alarmingly high to find the most appropriate support program for their children (Singer 1991).

The social life of parents of children with learning disabilities is quite different from those parents who do not have children with learning disabilities. Children with LDs are often considered weak social beings and are bullied not only in school but also in social gatherings (Sitlington 1990). Parents are often criticized and blamed for their child's LD which causes them to avoid or refrain from social interactions as they feel embarrassed or ashamed of the child's behavior or poor performance in academics. It is not only the child who faces bullying, unfortunately, but our society also lacks compassion and kindness towards the distressed parents due to lack of awareness. Parents are not only bullied by their family members but also by other parents who refuse to socialize with these parents giving rise to the feeling of isolation for them (Mearig.JS 1992).

Parents also struggle to get support and guidance from the educational institutes that refuse to take responsibility for helping the child. These parents are often left helpless with no assistance from the school administration. Examinations and assessments play a pivotal role in evaluating a child's performance but parents of children with learning disabilities need extra help or support programs from schools for their child to progress (Switzer 1985). Most schools fail to provide support, guidance, and counseling to these parents. Parents experience frustration as they work hard and struggle to enable their child in meeting his/her academic goals. Parents have aspirations for their children to become successful but with all the limitations and restricted resources, these children cannot reach their full potential which gives rise to feelings of disappointment in parents (Ow 2004). Even when the diagnosis is made parents find it hard to accept the stark truth of the challenges their children go through. In their constant struggle to make the best out of the given situation parents end up making mistakes in their upbringing which further worsens the situation. This also sometimes weakens the bond between parents and children and can cause them to grow distant from each other (Terman 1984). Parents should seek emotional counseling as they grapple with these challenges. They need to be more aware of techniques to help their children prosper and progress. Help and acceptance from family, community, and educational institutes can help these parents in their difficult journey.

3. Methodology

To discover the experiences of parents having children with a specific learning disability, qualitative research using interpretative phenomenological approach (IPA), focus group

discussions were used. Some of the open-ended questions asked during the focus group discussion are as follows:

What kind of a parent are you? E.g., strict, friendly, understanding, etc. What according to you are your child's strengths and weaknesses? How many times have you interacted with teachers regarding academics when your children were not doing well academically? What difficulties did you face with the teachers or what kind of behavior was shown by the teachers? What strategies did you use to prepare your children for exams? We all know that all the elite schools or above-average schools have some sort of arrangements for these children but they get stuck when it comes to Cambridge or matric exams. As a parent, what amendments do you want to have in our assessment system?

To have in-depth knowledge and analysis of parents with LD children, a qualitative method using interpretivism paradigms is a suitable research design. For interpretivists, reality is fabricated by individuals within society and shaped by people's views. They identify that people, having different backgrounds, norms and experiences fund the building of reality that exists in their wider social context through social contact. As these human perceptions and understandings are idiosyncratic, social reality may be modified and can have numerous angles (Hennink, Hutler, and Bailey 2011).

The objective of this phenomenological research is to explore the lived experiences of a phenomenon, in which the experiences and challenges faced by parents of LD children are explored. This method of phenomenology will emphasize the investigation of cognizant and instant lived experience and is subtle to the exclusivity of each person (Manen 2015). The outcome of the study would be helpful for all the parents with LD children to make amendments in their parenting style.

3.1. Sampling and population

The target population of this study is parents having children with learning disabilities in Pakistan. The sample participants will be purposively selected. To be suitable for this study, those parents whose children are in post-secondary grade and must be between 15 to 21 years of age were selected. Parents of children who are diagnosed with Dyslexia, Dysgraphia, Dyscalculia, and developmental disabilities like ADHD and ADD were included. Standard sampling was employed where the researcher looked for the maximum types of above-mentioned disabilities within the sample. Standard sampling is when all the cases happened to have some standard that is beneficial for the assurance of quality in a discourse (Creswell 2019). The criteria which were used to undertake this study was focus group discussions with five parents. When it comes to the question of the sample size there is no right answer as it depends upon the degree of commitment to the level of study of analysis and reporting, the productivity of the individual cases, and the limitations under which one is operating (Smith and Osborn 2007). Therefore, five participants meeting all the requirements were selected. For the selection of the participants, the researcher would be using her personal and professional contacts to find parents who meet the criteria.

3.2. Demographics of the participants

Table 1: The following table shows the demographics of Parents having LD children

Numbers	Names (Pseudonyms)	Gender/ Age	Profession
1	Parent A	Female/ 46 yrs.	House Wife
2	Parent B	Female/35 yrs.	House Wife
3	Parent C	Female/50 yrs.	Principal of a School
4	Parent D	Female/50yrs.	University teacher
5	Parent E	Male/57 yrs.	Businessman

Out of the five parents in the focus group discussion, there were four mothers and one father. Two mothers were housewives, one was the Principal of a private school and one was a University lecturer. The father was a businessman. All were above thirty years of age.

4. Findings and Results

The findings of the present study include the major themes and their sub-themes that emerged from the research question. Due to the COVID-19 pandemic, focus group discussions were conducted through Zoom, keeping in mind the health security of the participants as well as the researcher. The findings are in line with the following research question.

The themes originated, after the focus group discussion with the five parents, contain the struggle of the parents of LD children in preparing them to do better academically and socially. Out of the five parents who opted for the discussion, four were mothers and one father. Parent A was a school teacher and mother of Student A diagnosed with Dyscalculia. Parent B was a soft-skill trainer and mother of Student B diagnosed with Dyslexia, Parent C was a housewife and mother of a Dysgraphia boy, Parent D was a University teacher, mother of ADHD boy, and Parent E, father of Student E diagnosed with ADD, was a businessman. Two emergent themes with their subthemes are explained below concerning the participants:

1. Parents Challenges with the sub-themes of Parenting Style, Emotional Responses and Sufferings
2. Support from Academia with the sub-themes of Relationship with the teachers, Financial Stress and Modifications in Assessments/Examinations

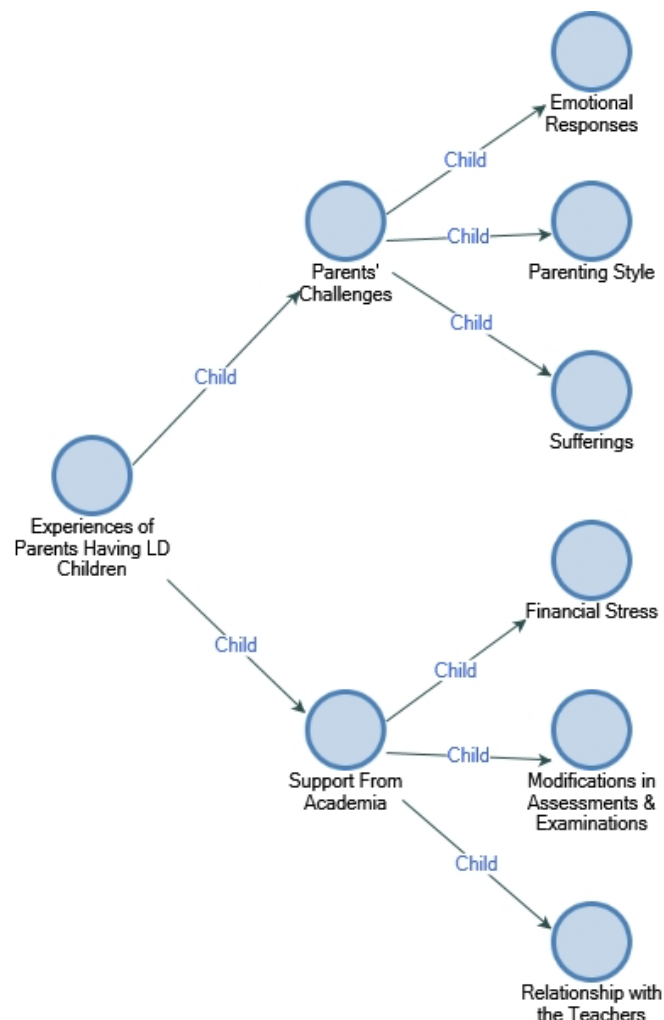


Figure 1: Experiences of Parents Having LD Children

When asked about their journey as a parent of an LD child, Parent E, who was a father of an ADD diagnosed child, described his journey with his son, a difficult one that sometimes seemed near but the terminus is far off. He also stated that not much research was being conducted on the parents of LD children:

“I will start by saying that this whole journey seemed sometimes too close but we know that the destination is very far off. Although much of the research is being done nowadays on LD students and their problems not much studies have been conducted on the parents of LD children.”

Studies have shown that parents of LD children face more psychological stresses than the parents of Non-LD children (Bdour, Beirat and Al-Bustanji 2019). Bdour et al. (2019) also states that the parents of children with any learning disability need more support in terms of their children’s educational and emotional needs.

All the parents in the focused group discussion had been facing problems with their LD children both outside and within the house environment. When questioned about their reaction to the diagnoses, the parents had mixed responses. Parent A defined it as a very painful and emotional journey. She states that she was in complete denial when confronted with the harsh reality. She even cried while narrating her journey with her LD child:

“I can never forget the day of her evaluation, when I was handed the report I was shocked and in denial. I kept thinking that how is it possible when nobody in my family has it and I do not have it either. I kept crying the whole time. I did not have a car so I was traveling in a rickshaw I kept crying in the rickshaw.”

While the research question deals with the lived experiences of parents having children with learning disabilities, the negative effects on the children due to their learning disabilities became a pivotal aspect of the research. Parents revealed that their children suffered from low self-esteem because they were constantly bullied and made to believe that they are not achievers.

Parents were asked about the support they received from the education system. They revealed that although some of the teachers tried to be supportive, sadly the education system does not provide any help or support for the children. In primary classes, the children find it easy to excel but as they grow older they find themselves stuck when they appear for Cambridge or Matric exams. These examination systems do not make any exceptions for these children, apart from giving extra time but they ignore the challenges in comprehension, reading, writing, and memory faced by these children. The education system does not have any exemptions for children and they are tested in the same way children without learning disabilities are tested. This puts the children under pressure and they go through high levels of stress which only adds to their struggle and challenges. The parents feel that the education system has no support for these parents and the constant struggle of their children puts added stress on the parents. They revealed that they had to spend a lot of time with their children in preparing them for exams and tests.

Parent B stated that *“Ever since I removed him from school he feels relaxed and does not feel the pressure of tests anymore. He is at ease.”*

The parents were presented with a very important question on their experience with the teachers. Parent A said that she had received great support from the teachers and found them to be compassionate but some of the teachers she interacted with were not very empathetic and understanding of their child’s learning disability. Parent B also had some mixed experiences with the teachers as she said that being a teacher trainer herself she would know all the teachers. The teacher’s to boost the confidence of her child sometimes gave him more marks. However, the administration did not approve of it and that made her lose her emotions and cry:

“They would be lenient with his marking but unfortunately, the whole education system does not support children with LDs. The science teacher would say that she is marking him

for the concept as his concepts were clear. Even his Urdu teacher would give him marks regardless of the kind of sentences he made. The head office of my school would get upset with this support. Sometimes I would break down as well."

Studies have shown that one of the reasons why students with learning disabilities leave higher education is the lack of understanding of the needs of LD students by the administrators of the school/college or the people involved in the assessment procedures (Barnard-Brak, Lechtenberger and Lan 2010).

Parents involved in this study had similar views. When asked about the problems they faced in preparing their LD children for the formative or summative examinations Parent A showed her dissatisfaction, more on the policies of our Government exam boards and Cambridge Boards. She was of the view that there need to be special arrangements in the curriculum as well as in the modalities of the exam papers for all LD students:

"Our government exam boards, as well as Cambridge, must cater to the needs of such kids in making the exam papers."

5. Discussion

The results of the finding after the focus group discussion with the parents of LD students showed that their whole journey with their LD children, right from the beginning of diagnosis to adjusting socially and academically, had been a daunting one. Each day is a test for them as almost every day they have to listen to the complaints of their child-related to academics, their social interactions at home, or their relationship with their teachers. The results also indicated that society is more suitable for typically developing individuals than for the learning disabled ones.

The discoveries showed that out of frustration and anger, some of the parents used to hit their LD child. This was mainly due to the low grades in the assessments and the parents compared the results with their non-LD children. However, all the parents in the study did admit their mistakes in handling their LD kids and tried their best to keep their learning process smooth by giving them every support. Parents participating in this study expressed their concern about the stigma that society attaches to the LD children. They get hurt when people consider their LD child as someone not to be associated with. Therefore, each one of the parents strongly condemned society in general and the school in particular in limiting their child's academic and social achievements. The findings also shown that sometimes parents might do some acts which according to them are beneficial for their kids but actually, that act could be harmful in the long run. For instance, doing the homework by themselves instead of their child just to show the class that the child can do it. The researcher was told by Parent D, the episodes of depression after the teachers would call her and advised her to work more with the child. She felt hurt as her child had no friends at school and he used to take out his anger and frustration at home. According to the literature review, the parents of LD children get very limited support from the family, community, or school as they are the ones who label their children and bully them for being intellectually disabled. These parents get emotionally disturbed upon seeing their LD child suffering emotionally as well as academically. As they are bullied by society and their peers at school they could not concentrate on their studies and lag behind. They are trapped in a vicious circle.

All the parents in the study reported having been suffering a lot due to the stigma attached to their children as learning disabled. This suffering is both in the child as well as in his/her parents. The lack of empathy shown by the school administration and teachers and also by the class fellows of their children had created negative effects on the LD child and his parents. The results also indicated that some of the parents of the non-LD students have been seen bullying the LD students within and outside the school environment. The findings indicated that due to the constant pressure of being accepted as other non-LD students were, the parents were of the view that this pressure was one of the barriers that affected their

child's academic performance as he/she could not concentrate on their subjects. These children are mocked, labeled and often face rejection when making friends. As a result, they do face stress, depression, and social anxiety. And because of this anxiety, their academics suffer.

The results from the focus group of parents revealed that because of limited awareness about individuals with learning disabilities in Pakistan, the support from the government is also limited. The education ministry is well aware of special children and physically disabled ones but very few have a deeper knowledge about learning disabilities. However, the findings also indicated that the private schools/ colleges do cater to some extent to the needs of LD students but their hands are also cuffed when it comes to their board exams or O or A-level examinations. The literature has also indicated that it is indeed a matter of concern that the education policymakers in the Pakistan government hardly mention the students with learning disabilities. Even the Right to Free and Compulsory Education bill, 2012, which guarantees free education to all the children in the age bracket of 5-16 years, as mentioned in Article 25A of the Constitution of Pakistan, seldom indicates LD children (Singal 2016).

The results gathered from the findings of the parent-teacher relationship were less positive and more negative. Except for parents A and B who had both good and bad interactions with the teachers of their children, the rest of the parents had bitter experiences with the teachers. The role of a teacher is to identify any student who shows any kind of learning disability (Tyagi 2016). Tyagi (2016) further stated that the teacher must involve LD students in all the school activities and the curriculum should be designed in a way that is supportive of these students. Moreover, regular parent-teacher meetings would be beneficial for the LD students as the parents would be getting feedback about their child. All the parents talked about a few of the teachers who lacked empathy towards their children and those were the ones responsible for the developing low self-esteem in their children. However, the parents did realize that the teachers were bound with the school policies regarding the exam pattern or finishing the curriculum at a specific pace. But they were of the view that a teacher could give extra time to their child to make him understand a concept, knowing that he/she had some learning issues. A healthy parent-teacher relationship could help support the academic achievements of LD students. The results of the findings are evidence of the fact that in a country like Pakistan with limited awareness of children with learning disabilities, it is the responsibility of the government and the school administration to organize professional development programs for teachers handling LD students. The scenario is even grave in the government schools as in those schools even the parents do not know about their child's learning disability.

6. Conclusion and Recommendations

The primary focus of this phenomenological study was to deeply understand the challenges faced by the parents of LD children in preparing them for their academic progress. The study also proposed that parental involvement in school activities is necessary for the academic development of LD students. Constant feedback by the teachers would keep the parents in the loop and they would be able to help their children at home in preparing for their assessments. The literature review mentioned a direct relation of parental involvement to the progress of their LD children. However, in Pakistan, very few parents have the chance to get involved in their child's school. Parents participating in the research blamed the school administration, faculty, and above all the government for not taking adequate measures for taking the examination of the LD students. They suggested various ways of conducting their exams like giving objective or MCQ-based papers, taking oral exams only, or making amendments in the curriculum. By doing these arrangements students would be at ease and would come out of the pressure of failing the class.

All the participants unanimously agreed that unless the government and the governing bodies will not intervene and take up the issue of learning disabled students with interest, these students will keep on suffering and lagging in academics. They suggested that a policy needs to be made and implemented regarding the assessment of these students.

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