Vol. (8), No. (1); 2022
ISSN : 2355-2069 (Print)
ISSN : 2656-5765 (Online)
Published by IAIN Bengkulu

LINGUISTS
JOURNAL OF LINGUISTICS AND LANGUAGE TEACHING

CHALLENGES FACED BY PARENTS OF CHILDREN WITH SPEECH DISORDER IN KOTO LAMO

ELDA SELJA PUTRI
IAIN Bukittinggi
eldaseljaputri@gmail.com

ABSHARINI KARDENA
IAIN Bukittinggi
absharinikardena@yahoo.co.id

DOI: 10.29300/ling.v8i1.6139

Received: February, 6th 2022 Accepted: April 1st 2022 Published: July19th 2022

Abstract

Parenting a child is difficult, but parenting disabled children is even more difficult. The complexity of a child's disability needs to be coupled with its complexity, frequently putting parental skills to the test. The experiences of three parents of children with speech disorders disabled children are examined in this study. A phenomenological framework and study strategy were adopted to collect data, including group discussions and individual interviews. The first participant in this study is J, who has a 17-year-old disabled son; the second is SY, who has a 4-year-old disabled son; and the last one is A, who has a 19-year-old disabled daughter. The researchers used content analysis in this study. Per review and member checks were used to improve credibility. The themes that emerged showed that parents had different experiences parenting their children with disabilities, as well as the need to provide parents with accurate information about their children's problems. It seemed clear that such parents would gain from counselling to help them cope with the problematic situations of raising a disabled kid. The author suggests that this study showed the challenges faced by parents who have speech disorders and disabled children, especially in Koto Lamo.

Keywords: Parent, Speech Disorder, Disabled children, Koto Lamo, Challenges

INTRODUCTION

The main purpose of this study was to show the challenges or explain the experiences of Koto Lamo parents of disabled children. Different types of disabilities that may manifest in some children's development have been identified in studies (Neeraja & Anuradha, 2014). Developmental and speech problems (Neeraja & Anuradha, 2014); Social and emotional disorders (Ferguson, 2014); and Social skills deficit disorders (Neeraja & Anuradha, 2014); and Social skills deficit disorders (Neeraja & Anuradha, 2014). (Leach, 2015). Academic skills disorders (Mackelprang, 2010); visual perceptual deficit; and behavior and adjustment issues are some of the others (Neeraja & nuradha, 2014). The following list of children's disabilities is by no means comprehensive.

How to cite this article: Putri, E. S., & Kardena, A. (2022). Challenges Faced by Parents of Children With Speech Disorder in Koto Lamo. Linguists : Journal Of Linguistics and Language Teaching, 8(1), 39-48. doi:http://dx.doi.org/10.29300/ling.v8i1.6139

Nonetheless, when parents find that their kid has a specific disability, they begin on a process that usually involves powerful emotions and difficult choices (Taderera & Hall, 2017, p. 1; Friantary, Afriani, & Nopitasari, 2020). The challenges faced by parents of children with speech disorder disabled are rarely reported by African scholars, according to Gona, Newton, Rimba, Mapenzi, Kihara, Vijver, and Abubakar (2016). Instead, the researchers point out that the majority of what is reported about the challenges faced by parents of disabled children is based on research conducted mostly in Australia, Europe, and North America (Gona et al., 2016). Taderera and Hall (2017) agree, noting that the majority of research on the impact of children's disabilities on families has been focused on Western experiences, with little attention devoted to the African study setting.

Despite the above assertion, multiple studies show that having a disabled kid has a significant effect on families, particularly the parents (Leach, 2015; Matenge, 2015; hildreCeka & Murati, 2016). Parents of disabled children feel bereft, bereft, and angry when they learn of their child's diagnosis (Neeraja & Anuradha, 2014). "The stress of living with a kid with [disability] might influence the psychological and emotional health of parents and produce conflict between them," Gona et al. (2016, p. 2) write. Having a disabled child in the family tends to take parents' focus away from other parts of family management, particularly the mother's (Elford, 2014). Furthermore, having a disabled child in the family places a stress on the parents' ability to allocate time and money to their healthy and unhealthy children (Ferguson, 2014).

When children are unable to communicate verbally, we can determine their needs from their gestures, body language, and even cries. Pre-verbal communication is what it's called (Bruner 1983). According to Bruner (1983, p. 39-42) there is a system called the Language Acquisition Support System (LASS) that allows the Language Acquisition Device (LAD) to function. In LASS, there is an interaction between the parent and the kid, which allows the LAD to function. As a result, we can determine that the contact between parent and kid impacts children's language acquisition abilities. According to another study, good connection is also a deciding factor in a child's language abilities (Murray & Yingling 2000).

Specific language disorder is a type of language disorder that focuses on a child's incapacity to create words without the presence of any other disorders. Parents must pay attention to their children, especially during some stages of development when the children's development does not correspond to developmental milestones.

Language development is linked to child-parent connection, according to the attachment perspective in social interaction. As a result, it's possible that language delays in children are caused by "unfinished business" in parental-child bonding. Meanwhile, a strong bond between parents and children is reflected in both parents and children's mental health. According to Urwin (2002, p. 75), *“Delays or difficulties in language development would then emerge as part of a broader problem in thinking unthinkable thoughts and in representing emotional experience symbolically. This puts the emphasis on the increasing fullness of mental life, which accrues from becoming a lan-guage user, rather than on what is given up. Ra-ther than language development distancing us from internal objects, it is part of the process through which we acquire them, and build an in-ternal word”.*

Meanwhile, according to Jones (2007), language or speech delays may be caused by a lack of relationship between the father and the children or because the father does not appear as a person who contributes in the separation-individuation process. Separation-individuation encourages children in the development of their self-object, a period in which they must recognize that they are individuals capable of doing various things, such as producing a word or beginning to communicate. Another fact that supports this statement is a study conducted by Klaniczay (2000), which claims that stuttering in children may be caused by the children's inability to separate from specific objects, or by the parents' anxiety, which influences child fear, resulting in stuttering in the children.

Parents with disabled children "had the issue of providing basic needs for their children," according to a research by Okeke and Mazibuko (2014, p. 14). Furthermore, Okeke and Mazibuko (2014) demonstrated that the level of education of the parents who participated in the study posed a significant problem. One of the consequences of this lack of knowledge was a lack of basic information. As a result, the most of these parents decided against going to their children's schools, even when they were invited to discuss their children’s health. Barbosa, Chaud, and Gomes (2008, p. 47) found that "healthcare professionals are frequently unprepared to deliver the family the diagnosis of disability, making this a traumatizing moment for the parents." When parents do not receive enough support from healthcare experts in managing their disabled child's needs, it might exacerbate the challenges already faced by the parents. Barbosa et al. (2008) go on to say that learning about a child's disability can have a number of negative effects for the family, particularly for the mother.

The birth of a speech disorder or disabled kid in a family, as studies have shown in this papers, proves to be some experience for the entire household. As a result of the real changes, the family life is emotionally unbalanced. Given this situation, understanding the challenges Nagari Koto Lamo parents face as they try to make a difference in the lives of their disabled children became important for these researchers. The researchers believed that such research would contribute to the understanding of how society as a whole can support them in effectively participating in the daily lives of their speech disorders’ disabled children. Despite the quality of empirical evidence in this aspect, it is unclear what sort and quality of information is accessible concerning the challenges Koto Lamo parents face, or what kind of support they require to effectively participate in the lives of their disabled children in the future. Furthermore, research must uncover compelling empirical evidence that might influence laws on effective support and treatment measures for families with disabled children.

METHOD

In this study, a qualitative research approach was used. According to Creswell (2014), qualitative research is an understanding inquiry process based on a distinct methodological tradition of inquiry that investigates a social or human problem, in which the researchers creates a complex holistic picture, evaluates words, reports detailed informant points of view, and conducts the study in a natural setting. Given this approach, choosing a phenomenological framework allows researchers to learn more about how participants in a study feel the topic under investigation (Matenge, 2015).

The parents of children from Nagari Koto Lamo who have speech disorders were the study's target population. There are three parents who have speech disorders disabled children. They are “I”, “SY” and “A”. Focus group discussions (FGDs) and semi-structured individual interviews were employed to collect empirical data in this study, as in phenomenological investigations. The FGD was chosen because it allowed researchers to collect data or information from a group of people in addition to the information collected through individual interviews. Furthermore, according to Cohen and Manion (2005), focus groups are particularly beneficial when time is limited and participants feel more comfortable discussing in a group than alone. Individually conducted interviews may be less revealing than interactions among participants. Furthermore, the FGD is cost-effective as a data collection approach, even in terms of money (Schumacher & Macmillan, 2010). The focus group interviews were used to extract parallels and contrasts in the parents' experiences raising and nurturing their disabled children. A focus group guide with ten questions, each with a theme and specific critical topics, was utilized to facilitate the FGD processes, and each session lasted 30 minutes.

A semi-structured face-to-face interview was employed to gather in-depth information about parents' experiences and challenges in raising and nurturing their speech disorder children with disabilities. The parents were asked open-ended questions to get direct quotes on their experiences, opinions, attitudes, feelings, and knowledge. More time was given for in-depth discussion of topics and personal accounts. All interviews were audio-recorded by the researchers in order to catch the exact words of participants, which helped to enhance the data collected. Through the use of eyes and voices, the researchers were able to gain a better knowledge of the person's behavior. Interviewees were involved in a comfortable and familiar environment. The duration of the interview varied depending on the individual, thus each one lasted between 20 and 30 minutes. In addition, an interview guide was employed to guide the flow of the interview.

In qualitative research, validity relates to the methodological soundness, validity, and length to which a study's reports accurately reflect the study's aims (Holloway & Wheeler, 2013; Elford, 2015). The degree to which the findings of this study on the obstacles experienced by Swazi parents of impaired children remain true to the parents' experiences of living with a disabled kid is referred to as credibility in this study. To establish credibility, the researchers conducted in-depth interviews and focus groups with individuals. The researchers then conducted member checks on the analyzed texts and transcripts, giving individuals the chance to verify the reports' veracity (Creswell, 2014). "Member-checks were carried out through [cell phone calls] with participants to disclose findings and allow participants to verify that meaning was appropriately captured," according to Elford (2015: 31).

The purpose of this phenomenological study of the challenges faced by Nagari Koto Lamo parents of disabled children is to discover key themes that will help to explain the meaning of the parents' lived experiences. The four "basic living world existentials [lived time, lived space, lived body, and lived social interaction] were applied as a frame to guide research," according to the study (Elford, 2014: 30). Individual interviews were directly listened to, then went through a process of discovery to find important themes.

FINDINGS AND DISCUSSION

Findings

The findings of this study are presented based on the challenges that the parents who formed the respondents expressed. In general, the findings demonstrate that parents faced numerous challenges in raising their speech disorder of disabled children. Challenges faced by the parent as follow:

1. *Socio-economic Conditions of the Parents*

Poverty was a major issue for the parents who participated in the study. In the study, parents stated that they were faced with difficult socioeconomic situations, which were primarily caused by financial challenges. As a result of their poverty, the respondents were limited in their ability to support. They were unable to send their disabled children to schools that were relevant and appropriate for their requirements.

"After discovering that our child had autism, we opted to enroll him in a rehabilitation center...[that] was incredibly helpful to the child," one of the parents

> *explained, "but the issues were that we couldn't pay the required fees each term, including transportation charges." (Interview data with parents)*

According to Chimhenga and Musarurwa (2011), some parents are unable to cover the high transportation costs to and from school because their children needs special transportation.

2. The Decision to Leave a Job for the Child's Purpose

Another issue raised by parents throughout the focus groups and individual interviews was the difficult decision to leave their work in order to attend to their child who needed support. One respondent stated that she had decided to quit her job in order to care for their child. When asked why she said she couldn't find a proper housemaid for him because most of them couldn't afford to care for him because of their behavior issues. Again, Chimhenga and Musarurwa (2011) found that in certain cases where housemaids were employed, children with disabilities were not properly cared for, especially when their parents went to work. The child was sometimes left alone, without food or sufficient care.

Another respondent (SY) who agreed with the idea of quitting their job to care for their disabled children had this to say:

> *"I was a farmer in Nagari Koto Lamo, but there are no special schools for my son in Koto Lamo, so I had to leave my job to care for him." (Interview data with parents)*

3. Loss of Family Independence

Another problem presented by the parents was the parents' and other members' lack of independence. Green (2007) argues that parents of disabled children generally raise their children in the setting of a powerful societal discourse that devalues disability, and that as a result, they are expected to feel emotionally troubled. The respondents reported that they spend more time caring for their children and less time engaging in social activities. They also have less active free time than parents of non-disabled children.

It hurts the parents to learn that their children are insulted and discriminated against by society. They believed that their children's social adjustment was affected by stigmatization and prejudice, and that this resulted in isolation or rejection. The majority of respondents stated that they were the ones who were most affected by their children's disabilities, and that they were always concerned about their children's social lives. One parent remarked, "That was confirmed by one parent."

> *My child finds it difficult to communicate or socialize with her friends, let alone visit family. We had to explain a lot about her educational background every time we went*

to see our relatives. That prompted me to decline her invitation to visit our family. (Interview data with parents)

4. Parents' lack of knowledge is to responsibility.

The majority of respondents stated that they lacked basic knowledge, ideas, and awareness about their children's disabilities. They also disclosed that they were unable to notice their children's problems in a timely manner owing to a lack of awareness. This difficulty was obvious in the parents' responses to the question of their awareness or knowledge of their child's disability. *"I had no idea my child had an intellectual handicap,"* one of the parents said. As a result, it took me a long time to recognize that the child needed to be placed in a special school." The study's findings found that the majority of respondents lacked expertise and information concerning their children's disabilities, making it impossible for them to determine what was wrong with their children. They voiced their belief that parents should be informed about their children's disabilities. Some others believed that the information may be shared or broadcast on television or radio. It might be distributed to community centers as well. This might be extremely beneficial to the parents, as some of them believe that if their children were made aware of their disabilities, they would know where to go for their rehabilitation.

5. Concerns of Parents as a Difficulty

The interviewees expressed serious concerns about their children's education, completion of school, capacity to get a job, and financial independence. Some parents worried about how their grown children would manage without them in the future. Where would they be able to live? What kind of financial and emotional support would they get? Would they be able to start their own families? Participants, on the other hand, expressed worry that, while they appreciate what the government of Nagari Koto Lamo has to give, they believe the government primarily cares about their children's academic needs, while neglecting the parents, who also need to be equipped with necessary skills. Such support for parents of challenged children, according to the participants, might be delivered through properly organized special programs including other stakeholders.

Discussion

The aim of this study to report the lived experiences of Nagari Koto Lamo parents of children with disabilities with speech disorders and it findings will used by government to help and support the parents who have disabled child in Koto Lamo especially. That is why phenomenology was chosen for the study bin since it allows researchers to learn about how parents who participated in the study experienced the phenomena of raising a child with special needs (Matenge, 2015). Parent participants in the survey said that their socioeconomic conditions, the decision to leave a career for the sake of the kid, loss of family independence, and special parental worries are some of the problems they face every day as parents of children with disabilities.

The participants complained their low socio - economic conditions, which they said made it difficult for them to care for their children. Due to a lack of finances, the respondents said they were unable to send their children to well-equipped schools that could help them rehabilitate their children. Some parents stated that they were unable to cover the high travel costs because some of their children require special transportation to and from school or rehabilitation facilities. This scenario was highlighted in the conclusions of a study on schooling children with special needs in the African environment undertaken by Chimhenga and Musarurwa (2011). Their findings found that some parents were unable to cover the high transportation costs to and from their children's schools because they need special transportation. This situation was complicated by the fact that some parents had to choose between leaving their job and spending more time with their disabled child. Of course, as observed in a research by Okeke and Mazibuko (2014), quitting one's employment meant that parents of disabled children faced the issue of meeting their children's essential needs. A lack of freedom on the part of the parents and children was also regarded as a critical issue for the parents. Green (2007) argues that parents of disabled children often raise their children in the background of a powerful societal discourse that devalues disabilities, and that as a result, they are expected to feel emotionally burdened. Parents devote more time to child care and less time to social activities, according to the findings of this study. They also have less active spare time than parents of non-disabled children. Mothers of disabled children frequently express role constraints and challenges in following careers as a result of the demands of parenting, implying that the most of them have chosen to quit their jobs for the sake of their children.

The sample size employed in the study is a major drawback that the researchers would like to point out. Despite the fact that the researchers identified parents of children with impairments, due to funding constraints and the time allotted for the study, it was difficult to engage all of the parents. It's also worth noting that some of the parents came from far away regions, mostly in rural areas of the country. It was difficult for the researchers to contact all of them as a result of this. Because of these limitations, readers should be cautious in extrapolating the study's conclusion.

CONCLUSION

It is certain that the parents who took part in this study faced several challenges that may limit their ability to effectively contribute to the educational development of their disabled children. More research, on the other hand, is required to enable our understanding of the situation. Professional counselling services should be made available as soon as possible. Parents of disabled children in Nagari Koto Lamo require counselling both before and after their children's diagnosis. This appears to be important, especially in terms of assisting them in coping with the reality of having a disabled child.

It is also suggested that parents form 'parents to parents support groups' for various disabilities so that they can share ideas as they deal with their conditions. This would allow parents to assist one another with coping skills for their children's ailments. It may, however, necessitate the cooperation of other players, such as non-governmental organizations in Swaziland that provide services to individuals with disabilities. This can help them with their socioeconomic and professional abilities. It is vital to inform the child's family members about his or her condition. Organizations that serve disabled people must make themselves known to the wider public through media programs that describe the services they provide.

The government of Koto Lamo, kec. Kapur Ix, Kab. Lima Puluh Kota, Sumatera Barat, must formulate policies and implement laws to prevent some disabilities from occurring as a result of parental carelessness or extreme conditions faced by new mothers, both are major factors in the development of stress. The government of Koto Lamo, kec. Kapur Ix, Kab. Lima Puluh Kota, Sumatera Barat, must consider the future of children and persons with disabilities by establishing more vocational institutes that can serve those who are no longer study at school. To help students with disabilities in the classroom, the government of Koto Lamo, kec. Kapur Ix, Kab. Lima Puluh Kota, Sumatera Barat, should consider introducing more relevant teaching and learning materials.

REFERENCES

Barbosa, M. A. M., Chaud, M. N., & Gomes, M. M. F. (2008). *Experiences of mothers of disabled children: A phenomenological study*. Acta Paul Enferm, 21(1): 46-52.

Bruner, J. (1983). *Child’s talk-learning to use language.* Oxford: Oxford University Press

Creswell, J. W. (2014). *Research design, qualitative, quantitative, and mixed methods approaches (4th Ed*.). New York: Sage Publications.

Chimhenga, S., & Musarurwa, C. (2011). Educating children with special needs: The African context. http://www.SAVAP.org.pk

Elford, L.M. (2014). *Mothers’ lived experience of parenting an infant/young child with special needs in a rural context.* Unpublished Masters Dissertation. Ontario, Canada:

The University of Western Ontario, Canada. Ferguson, G. (2014). Including children with disabilities in mainstream education: An Exploration of the challenges and

Ferguson, G. (2014). *Including children with disabilities in mainstream education: An Exploration of the challenges and considerations for parents and primary school teachers*. Unpublished Masters Dissertation. Dublin, Ireland: Dublin Institute of Technology.

Friantary, H., Afriani, Z.L., & Nopitasari, Y. (2020). The implementation of indonesian language learning for dyslexic in children at elementary schools in Bengkulu. *Linguists: Journal of Linguists and Language Teaching, 6*(2), 23-29.

Gona, J.K., Newton, C.R., Rimba, K.K., Mapenzi, R., Kihara, M., Vijver, F.V., & Abubakar, A. (2016). *Challenges and coping strategies of parents of children with autism on the Kenyan coast.* International Journal of Rural and Remote Health Research, Education Practice and Policy, 16, 1-12.

Green, S.E. (2007). *We are tired not sad: Benefits and burdens of mothering a child with a disability*. Social Science and Medicine, 64, 150-163.

Leach, D. P. (2015). *A phenomenological study of the experiences of parents of a child or children diagnosed with deafness*. Unpublished doctoral thesis. Columbia, USA: University of South Carolina – Columbia

Mackelprang, R.W. (2010). *Disability controversies: Past, present and future.* Journal of Social Work in Disability & Rehabilitation, 9, 87-98.

Matenge, B. (2015). *An exploration of the lived experiences of mothers raising children with autism.* Unpublished Masters' dissertation. Cape Town, South Africa: University of Cape Town

Jones, K. A. (2007). Assessing the impact of father-absence from a psychoanalytic perspective assessing the impact of father-absence from a psychoanalytic perspective. *Psychoanalytic Social Work* 14(1), 43–58. doi:10.1300/J032v14n01_03

Klaniczay, S. (2000). On childhood stuttering and the theory of clinging. *Journal of Child Psychotherapy* 26(1), 97–115. doi: 10.1080/007541700362186

Murray, A. D. & Yingling, J. L. 2000. *Competence in language at 24 months: relations with attachment security and home stimulation.* The Journal of Genetic Psychology 161(2), 133–140. doi: 10.1080/00221320009596700

Neeraja, P., & Anuradha, K. (2014). *Adjustment problems faced by children with learning disabilities impact of special education.* Indian J.Sci.Res, 5(1), 77-81.

Okeke CIO (2014). *Effective home-school partnership: Some strategies to help strengthen parental involvement.* South African Journal of Education,34(3), 1-10

Taderera, C. & Hall, H. (2017). *Challenges faced by parents of children with learning disabilities in Opuwo, Namibia*. African Journal of Disability, 6(0), a283. Retrieved from: https:// doi.org/10.4102/ajod.v6i0.283.

Urwin, C. (2002). *A psychoanalytic approach to language delay: When autistic isn't necessarily autism*. *Journal of Child Psychotherapy* 28(1), 73–93. doi: 10.1080/00754170110114800