**Parents Raising a Child with Autism: A Study of Challenges and Emotional Consequences**

**Introduction to Research and Evaluation in Education - EIPT 5033**

**University of Oklahoma**

**by**

**Abrar Hilal**

**Master of Applied Behavior Analysis**

**Instructor: Dr. Patricia L. Hardré**

**Abstract**

The lifelong nature of autism in a child causes many challenges and emotional consequences for parents and siblings; in particular, for those with specific socio-demographic characteristics. The aim of this qualitative research is to create a proposal, which will guide research on the challenges and emotional consequences that parents of children with autism face. In this study, a qualitative phenomenological-hermeneutic approach will be applied in conducting interviews and observations on these parents and their families based in Cleveland, Oklahoma. In this case, 75 parents will participate in an interactive interview while the researcher will interact with the families of 15 autistic children in order to observe their practices and what the parents go through on a daily basis. After the data is collected, the qualitative approach will further be applied in presenting this data through an arrangement based on a set of identified themes. This data will then be critically analyzed to come up with an understanding of the challenges and emotional consequences that these parents with autistic children go through based on various underlying factors.

**Introduction**

Autism is a developmental disorder that impairs a child's ability for social interaction, communication, and behavior and it becomes visible in the first three years (Moradi, Khundrakpam, Lewis, Evans, & Tohka, 2016). Autism not only causes struggle and difficulties in a child, but also causes many challenges and emotional consequences for their parents and siblings. Families with specific socio-demographic characteristics suffer the most. Parents raising children with Autism Spectrum Disorder (ASD) face higher levels of stress than parents raising children without ASD. One of the studies mentioned that "Parents face extreme difficulties in dealing with challenging behaviors, teaching their child to communicate, teaching basic life skills, guarding their child against danger, and preparing their child for adult life" (Bashir, Bashir, Lone, & Ahmad, 2014). However, a study also found that many families have resilience and positive attitudes while raising children with ASD because these family learn to adapt and deal with major stresses of their lives (Patterson, 1988).

Many families experience fear, concern, and grief when they come to know about their child having ASD. Eventually, families start to do the best to adapt throughout their children’s development (Karst & Hecke, 2012). However, one study found that when parental stress increases, both father's and mother’s resilience decreases. The study found that parental resilience is correlated with family resilience, even after taking into account how stressed the parents feel (Cripe, 2013). While some parents who have children with autism cope well with the additional challenges that autism brings, still their stress level is different from families who have children with disabilities. Nevertheless, both of the conditions can be devastating on the parents. To identify the distinct stressing points of the parents with autistic children, this study investigates the following questions: what are the challenges and emotional consequences encountered by the families who have a child with autism and how can we attempt to find ways to reduce those challenges?

**Research Purpose**

The purpose of this research paper is developing a research proposal that will utilize interviews to evaluate the challenges that parents undergo while raising a child with autism, particularly during the child’s young life, as well as the emotional consequences that they have to face. As a result, this will lead to the development of a conclusive paper that will create an insight on these challenges and the beliefs, social experiences, and practices that these parents adapt towards raising the children with autism.

**Research Questions**

In order to understand what the parents of children with autism undergo in the childrearing process, this paper will make use of a number of questions that will guide the feedback that the parents give to the researcher. However, these questions will be based on various underlying issues that prevail in family settings and will give the parents the flexibility and freedom to narrate their personal and family experiences. For this purpose, most of the research questions will be open-ended so as not to limit the scope of the feedback that the parents give. Moreover, the study is intended to have parents narrate their specific experiences, which might be distinct, even between parents of the same child. Additionally, a few open-ended questions will be utilized so as to shape the direction of the study and obtain basic and crucial details. The following set of statements and questions will thus be utilized:

1. Please tell me about yourself, your name, age, and educational level.
2. What is your family income?
3. How many of your children have autism?
4. Please give me the details of your child, including age.
5. When did you realize that your child has autism?
6. What was your reaction upon discovering that your child has autism?
7. What knowledge did you possess before the child was born regarding autism?
8. How do you rear your child, particularly since he or she is different from other children?
9. How do the other members of the family contribute to the childrearing?
10. Which challenges have you faced while rearing this child?
11. Are there long-term and short-term challenges?
12. Has this case been experienced by other members of your family?
13. What experience have you gained while bringing up your child?
14. How can you narrate your relationship between you, your child with autism, and other members of the family?

Through the use of these questions, the researcher will gain an understanding of how the parents learned of autism and how they handled the scenario. By giving the parents the flexibility to choose what they wish to share, the researcher intends to obtain a step-by-step narration that will help in understanding how the parents learned to rear their children with autism, if they encountered any difficulties, and, if so, how the parents will ultimately narrate those difficulties. Additionally, the researcher will have the opportunity to learn if the parents sought outside help, both financial and emotional, and the level of support that was accorded to them, both at the family level and from outside. However, the researcher is not bound only to these questions. Notably, these questions are open, unlike the open-ended survey questions used in quantitative research. As such, the parents may fail to give sufficient data as expected by the researcher, to which the researcher will consider other follow-up questions of a more inquisitive nature not necessarily stated herein.

**Research Methods**

**Design**

This study will apply a qualitative phenomenological-hermeneutic approach based on the Lindseth & Norberg (2004) model in both the research design and the analysis of the collected data. In this regard, interviews will be conducted on the selected sample, while observations will also be made on some of the participants so as to come up with data regarding the challenges that parents with autistic children face and the emotional distresses that might exist. Based on the interview questions, and with most of them being open-ended, it is expected that each session would take the parent a total of 1-3 hours. However, the observations will be different, as they will need more time and dedication. In this case, the observation phase is expected to take place for a period of three weeks, and it will be carried out at the homes of these children. Since the children are expected to be attending school, the observation phase will then be conducted on non-school days and after school.

**Sample Selection**

A total of 75 parents of school-going children with autism will participate in this study. 75 children will be selected from a total of 10 schools in Cleveland County, Oklahoma. This county is known for its highly diversified cultures, which will give the researcher an opportunity to cover various socioeconomic cultures during the study. In return, this will not only create a unified and all-inclusive study but will also help in understanding the disparities that exist between the different groups of people. Of the 75 parents, a total of fifteen will also be randomly selected to take place in the observation phase, which will be expected to last for a total of 3 weeks for each parent. Due to the high demand that is accompanied by this research, and particularly the observation phase, the study is expected to take a total of two years. Prior to visiting the schools, however, the researcher will seek consent from both the school and a local healthcare authority. This will equip the researcherwith consent and ethics forms that will be presented to the parents as a show of trust and confidentiality of the study. Moreover, this will also be necessary for creating trust and confidence among the parents through a guarantee of confidentiality, as well as creating credibility of the research.

After randomly selecting the schools, the researcher will explain the purpose of the study to the school heads and seek permission to interact with the parents of the children. At the same time, the researcher will request guidance from the school authorities in identifying children with autism and their residences. This will enable the researcher to generate a scatter map for these parents and thus have a clear and time-saving procedure to access them. The researcher will first need to contact the parents through phone calls so as to seek their participation in the study as well as setting up a date and time for the interview. First, the researcher will identify herself to parents and explain the purpose of their study and the benefits that it could create to the healthcare sector as well as to other stakeholders. The researcher will then request the parents to participate in an interview that should take a duration of 1-3 hours.

Upon acceptance, the researcher will further inquire of the parent whether they would be willing to have the researcher observe them and their family practices for a period of three weeks. Moreover, the number of parents who will take part in the observation phase will be limited to fifteen separate families. However, every parent will be interviewed independently, even if they are in one of these fifteen families.

**Exclusion Criteria**

There are factors that the researcher will apply in choosing the sample. First, the selected children should be living with their parents and not in nursing and primary care institutions. In this case, the child should have one or both parents. Additionally, they should be under the age of 12 years. The children will be selected in a way that both genders are included. The 12-year margin has been set so as to create an environment where the parents are most interactive with the autistic children. This conclusion was reached based on Harstad, Huntington, Bacic & Barbaresi (2013) findings that indicated a high likelihood of developmental improvement and independence beyond this age.

**Study Site**

The study will take place at different regions selected randomly within Cleveland County, Oklahoma. This county was chosen as an ideal site for this research so that relevant, reliable, and sufficient data would be availed. Notably, this is one of the most populated counties in the state, with a population of 269,340 as per 2013. (Lowitt, 2016). Furthermore, the county, and the state in general have experienced a drastic rise in the number of autism cases, which means that the relevance of this study to this region is very high. As per the Oklahoma Autism Network (2017), the prevalence of autism, particularly among the school-going age, has risen drastically in the recent past. This is despite the increase in the number of programs to assist parents and individuals in settling within the society and even more so in learning institutions.

**Data Collection**

This will form the most intensive phase of the study. As had been stated above, this process is expected to take a total of two years, which is due to the high demand of the observation phase that requires thorough observation for a period of three weeks for each family. However, the interviews will take a relatively short period of time. In each case, however, the process of data collection will be subject to acknowledgment from the parents of the participants. The process of data collection phase will form the initial part of a lengthy research process that will take a phenomenological-hermeneutic approach as suggested by (Lindseth & Norberg, 2004). According to Lindseth & Norberg, the data collection phases shape theoutcome of the analysis and consequently the findings of the study. Notably, this technique makes use of qualitative approaches that are then applied in the interpretation of a phenomenon. In the case of this study, the researcher is seeking to use observation and interviews to obtain data that will be analyzed to help understand the challenges and emotional consequences that the parents of children with autism undergo. As had been indicated, this study will take place in two phases.

**Interview**

After the parents have consented to take part in the study and set up a date, the researcher will visit the parents at the agreed-upon time. Visiting of the parents in their homes has been chosen so as to minimize the burden of both time and expenses that would fall on the side of the parents. Moreover, this will also create a chance to make helpful observations, particularly if the children is present. The researcher will make a re-introduction to the parent(s) and restate the purpose of the study. At this time, the researcher will have an opportunity to establish a rapport with the parents and the family. As noted by Rowley (2012), taking a short time before commencing an interview and establishing a rapport with the interviewee not only gives the interviewee and interviewer time to settle but also reduces the nervousness that would heavily affect the process of information sharing.

The researcher will be equipped with two sets of recorders, the consent form, a notepad, and a pen. The recorders will be used simultaneously. The purpose of the two recording sets is to minimize the chances of losing data that may arise when one recorder fails. In such an instance, the researcher may be forced to either postpone the interview or rely on manual data recording method, which is not only time-consuming but also fails to capture every detail of the data. Using the recording technique will necessitate close interaction between the interviewer and the interviewee, which is necessary to boost the information exchange. However, important points will be noted on the notepad so as to guide the areas of emphasis as the interviewer analyzes the information of the recording. Additionally, some instances, such as observed data and non-verbal cues, will not be captured by the recording device. As such, these will need to be noted elsewhere.

The researcher will pose the questions to the parents in sequential order, as had been indicated in the research questions section. This arrangement will necessitate the narration of events in a continuous way, which will also enable both the parent and the researcher to follow closely. In addition, it will minimize the possibility of confusion and thus lead to the collection of thorough and well-arranged data.

Other than the questions stated in this paper, this research will take more of an open and interactive nature. In this case, the questions listed above will only form a foundation of the research and provide the guidelines. However, how the questions are presented depends on what arises within the study. Being open-ended questions, they will give the parents the flexibility to give unrestricted answers but based on or related to the topic. In the same way, it is possible to have the parent answer a particular question within another. In this case, it will not be necessary to repeat the question. However, the researcher may need to pose follow-up inquiries not stated in the research questions in order to clarify the information. This will often arise when the researcher feels that the feedback is not sufficient of when there is something that needs clarification. Moreover, unlike close-ended questions, open-ended questions within an interview have no pre-defined answers, and thus the questions may be subject to change depending on the interaction between the two parties.

The questions are expected to take a duration of 1-3 hours, depending on the length of the feedback that the parent gives. In this case, the researcher expects different feedback and different experiences from different parents. Moreover, the parents have different backgrounds, and the children are based on different ages.

**Observations**

For parents that will have acknowledged participation in the observation phase, the researcher will spend time with the families and particularly at the times when the children are at home. The three-week period has been chosen since it creates sufficient interaction time. Additionally, it enables the family to adjust to the presence of a visitor in their homes and thus give them the first few days to resume their normal practices, even with the presence of the visitor. In this case, the observation data is expected to take a normal course after an average of three days.

The researcher will observe the daily routines of these parents, their families, and their autism children and make recordings on a journal and a notebook. This will enable chronological evaluation and analysis of the findings. Additionally, the researcher will interact with the families so as to ensure that they easily adapt to their presence.

**Data Presentation and Analysis**

In the phenomenological-hermeneutic model by Lindseth & Norberg (2004), the analysis phase involves a simple evaluation of the data so as to present ideas in a thematic manner. In this way, the identified themes will form the basis of evaluating the cross-sectional data and development of a unified set of observed behavior. As a result, the researcher will easily identify the challenges that the parents face as well as the emotional distress that may accompany the upbringing of autistic children. The thematic arrangement of this information will also enable the researcher to put into consideration the various other factors that may influence the challenges and emotional consequences faced by these parents, such as the socioeconomic level, presence of both parents, outsidesupport, the number of children who have autism, and others.

**Conclusion**

As per recent data, autism has risen to become one of the most prevalent health issues in Cleveland, Oklahoma, particularly amongst the school-going children. However, there is a lack of clear understanding as to what the parents of these children go through in bringing up these children. Despite there being knowledge on the presence of parental challenges, existing studies fail to account for the various socio-demographic attributes and how they shape the experiences of these parents. However, through a well-structured qualitative approach, this study will necessitate the collection and analysis of data, which will result in the creation of an informed report that not only states the various experiences of these parents but also analyzes them based on the background of the families.

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