## The Number of 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, those with specific socio-demographic characteristics. The aim of this study is to identify the socio-demographic characteristics of parents raising a child with autism in the Cleveland county population and then explore the challenges and emotional consequences faced. The research will be a case study focusing on a number of parents’ beliefs toward autism and emotional matrix for children with autism. The research will be quantitative in nature to measure the psychological dimensions of the parents of autistic children by using questionnaire. It will employ questionnaire for the purpose of providing an adequate level of comfort for the parents to feel confident and relaxed to reveal their emotions without any embarrassment when they answer the questions. Using a questionnaire will enrich the data concerning numbers of the challenges parents face on a daily basis with their children with autism. I will be interviewing 75 parents of children with autism. Research findings will be analyzed using thematic network analysis and emotional matrix. Finally, the results will be discussed and interpreted in terms of previous research and relevant theories.

**The purpose of the study**

The purpose of this research that measure the difficulties and the challenges faced by parents in raise a child with autism in the childhood period to gain an insight of the adaptations and beliefs of parents toward autism, their family, and social experience, health, and educational services.

**Research Questions**

This proposed study will seek to answer this central research question:

How many parents who are facing difficulties and challenges in raising children with autism in the childhood?

In addition, the following guiding questions have been formulated in order to guide the data collection process.

(a) How many hours you take care of your child with autism?

(b) How many families have outside help available to take care of special needs of all family members?

(c) The relationship between the parents and their child with autism?

(d) How many challenges and emotional consequences faced parents of child with autism?

(e) Does anyone in your respective families have autism?

(f) How many difficulties do you face on a daily basis when raising your child?

(g) How do you consider your relationship between you and your child?

The first question seeks to know how many parents spend their times with their children with autism, and these hours they spend with their children with autism enough or less. The second question seeks to know how many autistic children who receive support and assistance from the competent authority for the care of people with special needs. The third and fourth questions seek to know how many parents who feel resentful towards of their children with autism, and how many parents who feel happily about their children with autism. Questions five, six, and seven seek to discover answers about the family and the relationship between them and their child, and if they have family history with autism.

**Methods**

This study uses a quantitative design and applied a and a survey strategy. The survey strategy is used to collect data about characteristics, knowledge or opinions in a population. This study examines real-life experiences brought about by the existence of a child with autism in the family. The study addresses one research hypothesis:

1. How many parents who are facing difficulties and challenges in raising children with autism in the childhood?

**Sample identification and selection**

The questionnaire will be sent to 75 parents who have a child with autism from 10 schools at 3-month intervals for 1 years. The questionnaire will be for parents cover topics of information about them and their child. The intended population is residents of Cleveland county. These residents will consist of individuals of diverse socioeconomic backgrounds and races. Participants will be asked if they are 20 or older and must be at least the age of 20 to participate in the questionnaire. The questionnaire consists of three sections that were provided in the same order for all participants. The first section included general and demographic information. The second section includes questions specific to the child with autism, including their behaviors at home, live with single or both parents, and whether they were currently or previously in a parent support group or parent advocacy group for autism. The final section includes questions specific to the parents, include the number of hours they spend with their children with autism, restlessness or depression that faced them during raising their child with autism, their feelings about their children with autism, poverty, violence and parental problems.

First, I will ask the school permission and the parents with a consent form. Second, I will determine through school attendance how many students with autism attend the school.

Third, I will present the consent form and qualifications to the possible parents. I will explain to the parents the purpose of my study that will be a quantitative study that measures the difficulties and challenges faced by parents who have autistic children to the care of children younger than 12 years of age.

Then I am going to look at all the files of the children who have autism with permission from their parents who want to participate in the research to know what category they fall under. After collecting all the information about the child with autism and their parents then I determine if I need it in my research.

Then I will make three groups after I gather the information. The first group will be consistent autistic children who live with both parents. The second group consists of autistic children living with a single parent to know who has more difficulties and challenges for raising a child with autism. The third group is consistent with parents who have multiple children with disabilities.

**Study site**

I will conduct this study in one county of the Oklahoma: Cleveland. Cleveland county is home of the state’s largest comprehensive university, the University of Oklahoma in Norman. Although Cleveland county is the eighth smallest Oklahoma county in area, it has the third largest population with 2 of the state’s largest cities, Norman and Moore. Farming, oil production and horse breeding are important industries (CivicPlus, 2017).

**Data collection**

In this proposed study, the primary sources of data collection will be the questionnaire with closed‐ended questions, and interviews (e.g., face‐to face and telephone interviews, computer assisted personal interviewing) (Johnson & Christensen, 2016).

* **Questionnaire**

I am going to use a Web‐based questionnaire in this research because it will be easy for the participants to access it. The questionnaire will consist of three sections that will be provided in the same order for all participants. The first section will include general and demographic information (information about family history with autism, relationship to child, race/ethnicity, education, income, education, county of residence, etc.) (Rhoades, Scarpa, & Salley, 2007). The second section will include questions specific to the child with autism, including their behaviors at home, life with single or both parents, and whether the parents are currently or previously have been in a parent support group or parent advocacy group for autism. The final section will include questions specific to the parents, including the number of hours parents spend with their children with autism, restlessness or depression the parents faced during raising their child with autism, the parents’ feelings about their children with autism, poverty, violence and parental problems. The questionnaire will include: true/false, closed ended, and multiple choice questions. I will start the distribution of the questionnaire to the parents in fall 2017, at the beginning of the semester. The questionnaire will take 25 to 30 minutes to complete. Every week I will go to one of the selected schools for my study and give the parents the questionnaire. After 10 weeks I would have finished distributing the questionnaire to all the schools. Then I will collect the responses from the parents. After that I can analyze the data.

* **Interview**

The interviews will consist of oral questions asked by the interviewer and oral responses by the research participants. I want to use interviews in my research because some of the participation don't have a computer or phone, so the interview will be the best way to record their responses. These two methods were deemed appropriate for this study. So, I will conduct interviews face‐to face, via telephone, and over the computer. The interviews questions will be in the same format as the questionnaire and close-ended, so the participant will essentially answer the questionnaire during the interview. It will take about 25 to 30 minutes. All interviews will be tape-recorded.

* **Processes**

I am going to send the questionnaires to the parents and interview the parents who have a child with autism myself. So, after I gather all the information that I want, I will make three groups. The first group will consist of autistic children who live with both parents. The second group will consist of autistic children living with a single parent. The third group will consist of parents who have multiple children with disabilities. There will be 75 participants in the research, so the data collection will take 10 weeks for all the three groups. After that, I will want to see which group faces more difficulties and challenge in daily life raising a child with autism. The participants’ identity will be protected because the survey will be anonymous. Also, their right to answer or not answer the question will be protected by giving them a choice.

**Data analysis and management methods**

A baseline questionnaire will be administered to parents of child who have autism. Every two weeks I will collect questionnaires from parents. The data will be analyzed by Excel Survey. It is a web form, that can be designed to collect and store structured data into an Excel spreadsheet file (Leahy, 2004). This allows for re-tabulation and recording, if necessary, prior to analysis. The data will then be imported into SPSS, which will analyze all three groups at once (Hewison , 2005). Then, I will use a statistical analysis computer program to analyze the data and make observations. Also, I will be using questions from the F-COPES and CES-D, to assess coping skills and depressive symptoms to the parents of the child with autism (Churchill, Villareale, Monaghan, Sharp, & Kieckhefer, 2008).

**Conclusion**

Parents who have children with autism have more difficulties and challenges in their life like: dealing with challenging behavior, dealing with judgements from others, lack of support, impact upon the family, coping and the importance of appropriate support (Ludlow, Skelly, & Rohleder, 2011). The challenges were described as “never-ending,” which had a significant impact on the parents’ sense of well-being and ability to cope. The researchers mentioned that the challenging behaviors mostly included the child’s difficulty coping with changes to routine and the social implications of their child’s behavior. Also, they mentioned that some parents feel judged as “bad” parents or feeling like a failure and they faced difficult to deal with their child. So the parents need more help to overcome difficulties in their life (Ludlow, Skelly, & Rohleder, 2011).

One problem in my study is that the face-to-face interviews will probably be better for the participations than the questionnaire, but both of them have advantages and should be useful for analysis.

**References**

Churchill, S. S., Villareale, N. L., Monaghan, T. A., Sharp, V. L., & Kieckhefer, G. M. (2008). Parents of Children with Special Health Care Needs Who have Better Coping Skills have Fewer Depressive Symptoms. *Maternal and Child Health Journal, 14*(1), 47-57.

CivicPlus. (2017, February 8). *Cleveland County, OK* . Retrieved from Cleveland County, OK : http://www.clevelandcountyok.com

Hewison , R. (2005). Predictors Of Tertiary Level Performance in Non-English Speaking Background Students. *The University Of Western Australia*, 11.

Johnson, B., & Christensen, L. B. (2016). *Educational Research: Quantitative, Qualitative, and Mixed Approaches* (6th ed.). Thousand Oaks, CA: SAGE Publications, Inc.

Leahy, J. (2004). Using Excel for Analyzing Survey Questionnaires. *Program Development & Evaluation*, 1-28.

Ludlow, A., Skelly, C., & Rohleder, P. (2011). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology, 17*(5), 702-711.

Rhoades, R., Scarpa, A., & Salley, B. (2007, November 20). The importance of physician knowledge of autism spectrum disorder: results of a parent survey. *BMC Pediatrics*.