

Coping mechanism of families with autistic children essay



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CHAPTER 1 The Problem and Its Background Introduction Autism is a pervasive developmental disorder that affects the brain's development of social and communication skills and said to be a behaviorally-defined condition. (www. ncbi. nlm. nih. gov) a person with autism has to deal with great consequences due to the different adjustments they have to follow. Along with the stress felt by the autistic person, their families are the ones who should handle the responsibilities in raising their autistic children.

Since they have to raise the children with a disability, a big burden corresponds to the adjustment they have to initiate to their autistic child and for the whole family as well. Their responsibility is even more difficult since there are expenses due to the special needs that should be provided in raising their children with autism. The families' responsibility for their education along with daily care and acquisition of other resources and assistance is very demanding in every way.

Along with the material burdens inherent in raising a child with such disabilities, families deal with emotional and social conflicts as well. Behavior associated with autism may be a great stressor on the family, and have been associated with poor understanding among the parents and the siblings. At most times, the siblings experience anxieties from adapting to their autistic siblings because it creates great emotional stress from coping with the unusual behaviors exhibited by the children with autism.

The parents are the ones who are primarily affected by this situation, they have to deal with how they can provide their autistic children their special needs and another burden for them is teaching their other children to fully

understand the condition of their sibling with autism and how can they fully adapt to the changes and the effects of raising an autistic child to each of their children and for the whole family in order to be well-adjusted in raising their children with autism for them to live normally as possible. This study seeks to know the ways of a family in raising an autistic child.

The researcher is curious on how different families adapt to the effects of autism to their child and to the family. She also wants to know how they are coping to life and what kind of changes they have to undergo for them to provide the needs of the child and for the family and each members to function well and be well adjusted. Statement of the Problem The researcher would like to know the different coping strategies of families with autistic children. The researcher seeks to answer the following questions: 1.

Demographic Profile a. Number of the members of the family b. Age, gender and birth order of the siblings c.

Socio-economic status/monthly income d. Type of autism 2. What are the problems encountered in raising the autistic child? 3. What are the effects of autism to the family? 4. What are the ways does the family adapt to the different situations concerning the autistic child? Theoretical Framework This research used the Family-Systems Theory by Dr. Murray Bowen. According to Bowen, the family is an emotional unit and uses systems to describe the interaction among the unit and uses systems to describe among the unit. It emphasizes the interdependency of the family members rather than focusing on individuals in isolation.

Several principles from Family-Systems Theory appear to apply to autism as it develops within the family. They must create their family life cycle because the child is embedded within multiple systems which interact in direct and indirect ways to influence behavior. Among the systems involved in this interaction, the most important is the family structure which includes the parent-child subsystems, marital relationship and sibling subsystem and the consecutive roles of each. It is more recognized more and more that consideration must be given to the family system in planning interventions with the autistic child.

When the roles of each member are implemented to the family, it is now easy for them to interact with each other. The second principle of the Family-Systems Theory tells that behavior occurs within relationships that are characterized by reciprocal and directional interactions. With these two principles constantly followed, the family functions well and accordingly and benefits the whole family and each member. But raising a child with autism can create great emotional stress and can fully affect the family's system and interaction because of the problems related to autism.

For the family to form their organized family life cycle they must go through different adjustments and adaptation for the family's development, applying the third principle that says that any system functions as an organized whole. Research Paradigm Raising a child who has been diagnosed with autism can be a very challenging role for any family. Since they are the ones who are primarily responsible for dealing with the needs of the child with a disability, they also have to deal with great stress regarding the autistic child.

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The presence of a child with a disability may involve some difficult adjustments for the rest of the family. Different effects are implied to the whole family, changes in family roles are highly affected and because of this they have to reorganize the family's functioning and activities. Autism affects the enormously, they are challenged physically, mentally, emotionally and financially as well. Everyday things have to be carefully planned and executed. Families are somehow put into situations where they can't afford to take care of them, other children are neglected in some ways and everyone ends up stressed out.

There's always tension between siblings, but when one child has a disability, things can get more complicated due to lack of understanding concerning the autistic child which can become another great problem. These problems regarding the autistic child can be an extremely great stress to the family. For the family to give the autistic child their special needs and for them to somehow prevent and minimize the problems caused by the effects of having an autistic child, they have to make different adjustments for them to live normally.

It is important to educate the whole family about the conditions of the autistic child for them to fully adjust to different kinds of effects of autism and as well as raising the child with the said condition. Significance of the Study The researcher believes that the study would be beneficial to the following people: Autistic Child. This study will provide different ways of attending the needs of the autistic child for them to live easily as possible. Families with autistic children. This will help them in adjusting, coping and treating the autistic child which will be beneficial in raising the child and for <https://assignbuster.com/coping-mechanism-of-families-with-autistic-children-essay/>

the family to live normally. Members of the community. This will be a guide for the people to understand well the situation of autistic children and as well as treating the families who are raising them. Psychologists and other related areas. With this study, they should help the families by introducing ways to cope properly and attending the needs of the autistic child. Future researchers. This can serve as a reference for future studies related to the topic. Scope and Limitations of the Study

The researcher aspires to determine the coping mechanism of families with autistic child. It will focus on the families' ways of adapting to the different situations concerning the autistic child, it will also tackle the problems they have encountered caused by the effects of raising their child and how they adjust to live normally as a whole family together with the autistic child. The study will not talk about the public's treatment to the autistic child and to the family and as well as the very private issues regarding the situation of the child.

Due to lack of reference, some of the related literature used by the researcher was below the year 2005 because there were only few studies and literature related to the topic specifically local. Definition of Terms For better understanding of this study, the following terms have been operationally defined. Adjustment. Refers to the behavioral process of balancing conflicting needs or needs against obstacles in the environment. Autism. A pervasive impairment in important areas of development. Coping Mechanism. Ways used by individuals to overcome anxiety and stress.

Family. Basic unit of the society affiliated with each other. Full Adaptation. To adjust fully from a certain stressful situation.? CHAPTER 2 Review of Related Literature This chapter presents the review of the related that will help the researcher to further shape her study. Foreign Literature Autism has been termed a “ family epidemic” according to Cecelia McCarton MD. She said that all members of the family are affected by autism, she tells that five main areas of family functioning are totally affected and have stated different family issues concerning autism.

It tackled parental expectations on how they have to adjust, the worries about the siblings of the autistic child, maintaining the family traditions and usual activities and on how they should keep a healthy social life. These autism-related issues that families have to deal with are similar, whether the child is severely affected or has high-functioning autism. (Kathleen Doheny, May 28, 2008) Evans (2006) stated that having a child diagnosed with autism can be a challenging role for the family. The family is like being in a roller coaster of emotions as time goes living with the autistic child.

She also stated that the parents are the ones who receive heavier responsibility specially the mother who often feels the impact of their child’s autism more personally than others; the mother may experience additional emotional stress since the main role of raising the child falls to them. She said that having an autistic brother or sister also impacts on their siblings, they might feel embarrassment towards the situation of their autistic sibling and may be reluctant to bring friends to their house or may be jealous of the time spend by their parents to their autistic sibling.

On the other hand, Evans said that there's a positive outcome for having an autistic sibling, because they may develop strong feelings of protectiveness towards their brother or sister with autism. Evans also stated some ways of reducing the impact of autism on the family. She said that the parents should always recharge their relationship by keeping their moral up for them to stay motivated which can be apply to the rest of the family. (Rachel Evans, August 7, 2006)

Evans (2006) said that sibling rivalry can become even more pronounced when one child has a mental or physical developmental disorder. The parents should do things to improve the relationships between brothers and sisters when one child suffers from autism. It is important for the parents to educate their children about autism; they should explain to their children that their brother or sister has a different understanding of the world, their sense of responsibility for a sibling who needs help can create more understanding.

The parents and their children should get involved in exchanging to educational games for them to play together The parents should also remember that their non-autistic child needs plenty of care and attention as well so they should learn to balance things and events so everyone in the family can learn to interact peacefully with one another. As stated by Evans, when there is a level of understanding between children and their parents, the family can work together to help their autistic member, as well as help one another to be successful in life. Rachel Evans, October 21, 2006)

According to Hillman (2007) the most effective treatment for children with autism appears intensive, requiring many hours a day across many settings <https://assignbuster.com/coping-mechanism-of-families-with-autistic-children-essay/>

in order to gain the best treatment compliance and to bolster treatment effectiveness. In other words, therapists must treat the entire family of the autistic child. Of all the family members, mothers of the children with autism appear to possess the most psychiatric symptoms, and estimates suggest that between one and two-thirds meet the criteria for clinical depression.

Mothers and fathers of children diagnosed with autism are more likely to feel less confident in their parenting and to experience greater marital distress than parents of typically mentally retarded children. So from the beginning, the mental health of the parents must be considered immediately, particularly on the time of diagnosis. Where parents with a child with a diagnosis of autism must be fed with more information and more possible interventions and parents must have adequate social support. (Hillman, 2007) The siblings of children with autism are assumed to be the caretaker of their sibling which creates a unique bond among them.

The siblings of the children with autism have a special connection with each other which is usually lifelong. So the parents must educate, motivate and support positive relationship exhibited by their non-autistic child for the benefit of their autistic child and the whole family. Aspects such as age, temperament, personality, birth order, gender, parental approach and role modeling varies the intensity of the relationship of the siblings which parents must take control. Some siblings of children with autism have negative experiences, at most they will experience anxieties, sense of anger, jealousy, embarrassment, loss and loneliness but the good news is that these siblings often turn out to be more compassionate, and thoughtful than average.

These siblings have seen what it's like to have difficult moments in life and <https://assignbuster.com/coping-mechanism-of-families-with-autistic-children-essay/>

eventually they will be more patient, tolerant and compassionate and now have the knowledge in handling difficulties in life. (www. brightots. com, August 23, 2011) Local Literature Carandang (1996) stated that a special child, whether autistic, gifted or retarded requires some special adjustments from family members. In dealing with special children, parents should be reminded to make use of the total-person approach.

This total-person approach should be their continuing guide and framework for parenting. This total-person framework also becomes a constant awareness that every step of the way of whatever aspect in the child's growth might be lagging behind concerning the child's condition. (Ma. Lourdes Carandang, 1996) A book that stated a whole understanding about children with special needs specially the Filipino child with special needs. They have tackled the basic needs of the special child and how to address it to them, from their basic care, safety check and other parental control.

They also stated on how to meet the child's needs in sensory-motor, cognitive, social and emotional by preparing different kinds of exercises and activities. Isaac et al have stated different approaches in taking care of the special child, they also have prepared different kinds of prevention and remedial action whenever problems occur concerning the situation of the special child. They also stated that the community can be a big help in the primary care of the special child if they are well educated about the situation of the child. Lastly they have tackled different issues regarding the special child from sibling issues and handling stress. Cynthia Isaac et. al, 2005) A biographical book about a family's struggle with autism, as narrated to

Alejandro R. and Santos V. ; the family's difficulties and successes in <https://assignbuster.com/coping-mechanism-of-families-with-autistic-children-essay/>

addressing autism in one of its members. It has stated on how they learn about autism, its symptoms and methods in managing it, in finding out how a child with autism roused the family up from a life of comfort and complacency to one of concern and social action. It also tackled on how consciousness about autism in the Philippines grew from the 1960s, when it was hardly known, up to the present.

It showed how family's love and devotion to a family member can break barriers of a disability and even showed that even one child is said to have autism can still be a great help to them. (Alejandro R. et. al, 2009) Foreign Studies Altieri and Kluge (2009) analyzed family dynamics and coping behaviors of parents with a child with an autistic spectrum disorder. This research suggests that moderate levels of cohesion and adaptability are associated with higher levels of positive coping, and that the more coping strategies a family implements, the greater their satisfaction with family functioning.

Using a family systems approach, the relationships among the familial variables of cohesion, adaptability, and social support were evaluated for their contributions to coping in the family unit. They also compared the responses of mothers and fathers. Surprisingly, for these parents of children with autism, those who rated their family as enmeshed implemented more positive coping strategies than did those from other cohesion styles as stated by Altieri et al. This finding suggests that the enmeshed style may be more adaptive for a family that encounters extreme challenges.

Notably, mothers and fathers agreed on all variables except for perception of social support from family and friends. Mothers perceived more social support from family and friends. (Altiere, M. et. al, 2009) Lee (2009) investigated the coping differences in relation to the psychosocial adjustment (depression, anxiety, and marital adjustment) between mothers and fathers of children with and without High Functioning Autism Spectrum Disorders (HFASDs). Parents of children with HFASDs and parents of children without any disability completed a packet of psychological survey.

Statistically significant differences were found between the HFASDs and control groups in depression, anxiety, one subscale of the marital adjustment measure and four subscales of the coping measures. When compared across gender within the HFASDs group, depression, anxiety, one subscale of the marital adjustment, and four subscales of coping were found to be statistically significant. Parents of children with HFASDs exhibited less adaptive coping skills as compared to parents of children without any disability.

Mothers of children with HFASDs exhibited more adaptive coping skills as compared to their father counterparts. Interaction effect of disability and gender, however, was not significant. (Lee, Gloria, 2009) The study examined the profile of stress in mothers and fathers of preschool children with autism, Down syndrome and typically developing children. A further aim was to assess the association between parenting stress and coping style. The results indicated a higher level of stress in parents of children with autism.

Additionally, an interaction effect was revealed between child diagnostic group and parent's gender for two scales of parenting stress: dependency and management and limits of family opportunities. Mothers of children with autism scored higher than fathers in parental stress; no such differences were found in the group of parents of children with Down Syndrome and typically developing children. It was also found that parents of children with autism differed from parents of typically developing children in social diversion coping.

Emotion-oriented coping was the predictor for parental stress in the samples of parents of children with autism and Down syndrome, and task oriented coping was the predictor of parental stress in the sample of parents of typically developing children. The results strongly supported earlier findings on parenting stress in parents of children with autism. They also shed interesting light on the relationship between coping styles and parental stress. (Dabrowska, A. et. al, 2010) This study draws attention to the stress levels and coping strategies used in the families of children with autism.

Differences in the stressors perceived and coping strategies adopted by the father, mother and siblings of a child with autism have been discussed. Given that pre-intervention parental stress levels predict the success of early intervention programs and determine the prognosis, this highlights the importance as well as the lack of providing psychosocial support to the families of children with autism. The researchers have illustrated various ways of delivering effective support services for parents. The study progresses from child entered, professional dependence for service delivery to developing strategies that are family centered and encourage active

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participation of parents of children with autism themselves. The paper also draws attention to the prevailing scenario of autism in India. (Gupta, A. et. al, 2005) The purpose of the study is to serve as an exploration of family experiences in relation to a child's autism diagnosis focusing of family adaptation. Given that mothers play a crucial role in the family system and are often the primary caregivers for children with disabilities, maternal adaptation is also investigated.

Families of children with autism experienced multiple stressors, and through the mediating influence of coping strategies, they discovered useful resources, redefined their circumstances, and progressed toward adaptation. Mothers followed similar patterns of adaptation personally, though some elements of maternal adaptation were predictably different from those of other family members, given the responsibilities of a parental role. Findings of this study yield insights into social and cultural influences and related adaptations among families of children with autism. Williamson Stephanie, August 2009) Local Studies A study conducted by Pasana (2011) attempted to determine the adjustment mechanism utilized by male and female parents of children with autism. This study indicated that the female and male parents of children with autism often used the adjustment in terms of intrapersonal relationship, it is also evident in this study that the parents sometimes utilizes the adjustment mechanism in terms of interpersonal relationship. Both of the parents utilize the adjustment mechanism in dealing with their economic problems, social issues and personal growth. Pasana, Mary Rose, 2011) A child with a disability can have a profound effect on the family especially the parents as stated by Tuazon (2006). However the

extent of the nature of effect is not always certain since families react in varying levels of emotional and physical stress. This study focused on the different stages of grief of the parents upon learning that they have a special child. There is significant and positive relationship between the selected parental profile of the parents when grouped according to gender of children with disabilities and the stages of grief since the parents differed greatly in how they overcome grief and adjust emotionally to the situation of family confronts. This study proposed modules in intervention coping strategies for parents of exceptional children will help the parents of children with special needs cope up with emotional grief and stress. In addition, they will be more enlightened and tolerant, not only for the special children but also of others as they make them better handle the grief and stress with the use of different strategies. Tuazon, La Verne, 2006) The study focused on the coping mechanism of parents with special children and the demographic variables and the relation of each to the topic. They have found that problem, emotion and interpersonal does not have any relationship with the demographic profile of parents. It is also stated that parents with special children experiences poor coping patterns evolving from faulty learning but knowing the fact that they belong to an intact family makes them cope effectively in handling problems, emotions and interrelationship. Chua M. et. al, March 2003) Carandang (1998) has stated the significant difference between the siblings of autistic children and non-autistic children on the quality of their sibling relationship. The study also tackled the difference between the mothers and siblings in describing the quality of sibling relationships of autistic children and non-autistic children. This study also

covered the differences of the perception to the quality of sibling relationship regarding the gender of each sibling. (Carandang, M. L. , 1998)

Liwag (1987) has stated different family-related demographic characteristics and their relations to the autistic children. She also described the parental characteristics of the families of Filipino autistic children. This study focused on the coping patterns utilized by the families in living with their autistic children and the stresses associated with their autistic children. (Ma. Emma Concepcion D. Liwag, 1987) Synthesis The data gathered by the researcher supported the meaning of the coping mechanisms of the families with autistic children and the effects of it to the whole family.

The researcher's literature and studies strongly support the topic of the researcher. The foreign and local literature have further discussed the effects of raising an autistic child to the family, the adaptation and adjustments and the coping mechanisms the family has to follow for them to live normally. The foreign and local studies have the facts and the situations which provided the appropriate data that the researcher can use in her study than can help to reinforce and can make the results stronger. CHAPTER 3
Research Methodology

The researcher has followed the following research methods: Research Design This study used a qualitative research specifically the grounded theory method. Its goal was to examine human experiences, gather, understand, interpret and analyze personal accounts on stories of the adjustment of families with autistic children. It included insights, feelings and emotions of the families regarding their children with a disability, the

problems they encounter, the effects of autism to the family and their coping mechanisms. This study is considered formal, in terms of problem identification.

It also described as a life story method in gathering data wherein the researcher used the method of in-depth interview with the respondents, allowing them to freely talk about their lives, thoughts and feelings and disclose detailed personal experiences. With respect to time dimension, the research design is cross-dimensional considering that it conducted over a span of time. Moreover, this study is basically non-statistical since conclusions are based on the results of the interview. And finally, the research environment is conducted in a real-life situation. Hence, the research design of this study is best described as multi-faceted Population and sampling plan This study will use the purposive sampling design which known as the judgmental sampling design. In this design, the researcher uses her good judgment in selecting the respondents who will best meet the purpose of this study. Research locale The interview will be conducted in each of the respondents' residence, so that they should be comfortable in the interview since their home is considered as their comfort zone. Research instrument The research instrument to be used in this study is a guided questionnaire prepared by the researcher.

However, this is just a guide and the researcher will allow a freewheeling discussion at the convenience of the interview. There will be no force or coercion whatsoever but the researcher will devise a way to make the interviews to be more open. This will be the basis of the in-depth interview, based on a prepared interview schedule to be conducted with each

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respondent. The data will be gathered by means of taking notes since the researcher will allow the respondents to use their own words by narrating their feelings, views and opinions. Data Gathering Procedure

To gather the necessary data, the first step that the researcher will do is to present a request letter to each of the family with autistic children to seek permission to conduct an interview. After getting the approval of request, the researcher will start the interview. The data will be gathered by means of note-taking or coding by the researcher while the respondents are narrating their stories. During the interview, the researcher may intervene either to clarify words or statement, ask to elaborate on important events or simply motivate the respondents to relate further.

After the interview, the researcher will thank the respondents for sharing their stories and she will analyze and interpret the results of each interview. Non-statistical treatment Since the researcher uses a qualitative research design, hence there are no statistical tools to be used to analyze the reviews the researcher will answer the statement of the problem per part: a. Coping mechanisms of families with autistic children. b. The effects and adaptations of each family member regarding the situation of the autistic child.

For each part, the researcher will analyze the results and she will then compare interview to interview and then the researcher will sort out each interview. After the said processes are done, a grand summary will be used to have an overall picture of the results of the study. ? Bibliography Books Alejandro, R. , & Santos, V. (2009). Our Andrei: Living with autism. Quezon City: Carandang, M. L. (1996) Filipino under stress. Quezon City: Ateneo de

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