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SOCIAL SUPPORT SYSTEM FOR CHILDREN WITH AUTISM IN MANDAUE CITY, PHILIPPINES

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ABSTRACT

Background: Social support has been found to be a major component of adaptive coping in parents of a child with ASD or an intellectual disability. Child ASD characteristics, especially their cognitive limitations and the long-term dependency that ensues, have been associated with mothers' urge to seek social support. Moreover, mothers of a child with ASD who reported being under greater stress have reported being more inclined to pursue social support. Most parents in this study sought knowledge from the internet in regards to their child's condition rather than consulting the doctors that give the diagnosis to know more about the diagnosis.

Findings: This indicated that no relationships were formed between the health care providers and the clients. This study reinforces the need for more support for parents with a child with autism especially during the diagnosis and throughout visits to mental institutions when seeking therapy. Autism is a lifetime disorder that warrants lifetime intervention because change is continual. Lack of knowledge and understanding about autism, parents' attitudes on the disorder and misdiagnosis are the major reasons for delayed diagnosis.

Recommendations: This research has indicated that strong family support system leads to positive coping; therefore nurses should offer continual support for parents with a child with autism when they visit any health care facility, this will help prevent anger build-up in parents protecting the child with autism from child abuse.

Keywords: *Social Support System, Children, Autism, Mandaue City, Philippines*

INTRODUCTION

Autism spectrum disorder (ASD) is one of the most serious development disorders and its prevalence is systematically increasing (Hess, 2019). According to the World Health Organization statistics, 1in 160 children suffers from autism spectrum disorder worldwide (WHO, 2019) whereas according to Autism Europe association, autism affects 1 in 100 persons (Autism-Europe, 2019). Having a child with autism has both positive and negative impacts on the other typical children. Siblings tend to develop a sense of maturity and take pride of greater sense of responsibility faster than their peers. They take pride in the accomplishments of their brother and sister and develop a strong sense of loyalty. Siblings of ASD children are usually more tolerant of differences in people and show the compassion for others with special needs. However, many siblings feel resentment at the extra attention the child with autism receives, and some feel guilt over their good health. They may also feel burdened with what they perceive as parental expectations for them to be high achievers. Many feel anxious about how to interact with their brother or sister, and feel rejected by the lack of reciprocity. Often there is a feeling of resentment at having to take on extra household chores, coupled with restrictions on social activities. A study conducted Griffith, Hastings and Petalas (2014) demonstrate that both mothers and fathers rated siblings of children with autism as having significantly more emotional problems and lower pro-social behavior than the normative population.

Social support has been found to be a major component of adaptive coping in parents of a child with ASD or an intellectual disability (Behrani & Shah, 2016). Child ASD characteristics, especially their cognitive limitations and the long-term dependency that ensues, have been associated with mothers' urge to seek social support. Moreover, mothers of a child with ASD who reported being under greater stress have reported being more inclined to pursue social support (Sharabi, & Marom-Golan, 2018).

Social support has been described as a vital resource for families with children with autism. Social support is categorized into informal and formal support. Informal supports are described as those that come from a network that may include family, friends, and parents of other children with disability. Informal supports play an important role helping caregivers reduce the feelings of isolation and helplessness often associated with raising a child with a disability (McIntyre & Brown, 2018). Formal supports are provided through an organization or agency, such as medical professionals, school staff, and day care providers.

Parents of children with ASD tend to first seek formal social support, such as medical doctors, respite care, psychologists, social workers, and special education teachers, to aid in caring for the child (Meral & Cavkaytar, 2012). These parents express appreciation for formal support, noting that it provides relationships with service providers in their child's early intervention program. They pinpoint the important role of service providers in helping those learning new skills and conveying knowledge to help their children (Coogle et al., 2013). After acquiring formal social support to fulfill the physical and psychological needs of the child, parents typically seek informal social support, such as family members outside of the home, friends, and support groups.

Parent support groups that emphasize sustaining couples' relationships during times of is beneficial for families with children with ASD (Ekas, Timmons, Pruitt, Ghilain, & Alessandri, 2015) especially when children exhibit more intense behavior problems and are difficult to control. The study conducted by Santoso, Ito, Ohshima, Hidaka and Bontje (2015) on resilience in daily occupations of Indonesian mothers of children with autism spectrum disorder showed that parents' greatest concern was for their children's future. The results of this study further shows that creating and re-creating accepting conditions such as support from family members and other people from the environment , involvement of father in the child care and understanding of the child's condition among extended family members is fundamental to mothers' resilience by easing their emotional and practical burdens (Ohshima, Hidaka, & Bontje, 2015).

RESEARCH METHODOLOGY

This study used phenomenological qualitative research design. Phenomenology qualitative research is conducted to comprehend the contexts within which informants engage with an issue (Polit & Beck, 2004). The study was conducted at Cebu Kid's Center for Autism Foundation, Mandaue City along BasakLabogon road close to Basak Elementary school.

Snowball sampling was the sampling technique used in this study. An occupational therapist directed the researcher to some of her clients with children with autism who further introduced to the researcher to other parents who had a child that suffered from autism. This means that the subjects were recruited from existing acquaintances. The informants who were willing to participate in the said research shared their experiences without coercion. This sampling technique led the researcher to nine (9) informants that were difficult to assess. The researcher stopped getting more informants because at the 9th informant data saturation point was reached. The researcher got the informants from Cebu kids Center in Mandaue.

Parents with autistic children ages 3-12 were recruited. Any parent (father/mother) that was willing to participate in the study and spoke English, irrespective of their educational attainment or socioeconomic status was included. The study excluded the siblings and the house help of the children with autism. Data was collected through the use of semi-structured face-to-face interviews. Formulated questions were used to guide the conversation. The informants were audiotaped to aid later in the transcription phase. The questions formulated were open-ended and provided the research informants an opportunity to express better themselves. A pilot study was conducted before the actual research that served as a trial run of the developed instrument (Polit & Beck, 2004) which yielded similar results to the actual study. Pre-testing the questionnaire helped ensure the validity of the study by making sure the questions are clearly understood. Research informants that participated during the pilot study were not included in the actual study.

The researcher did bracketing before data gathering. She examined her personal biases, experiences, past knowledge about the research topic to a fellow researcher. She later wrote all these biases down and kept a journal during interviews writing down every bias that arose.

The researcher requested an occupational therapist to refer her to some of the parents of her clients with Autism that met the criteria established by the researcher. The informants were contacted telephonically by the researcher to obtain consent and set up appointments. The researcher went to the venue suggested by the research informant that the interview should be conducted. The interviews were conducted in English depending on what the research informant was comfortable with. The researcher explained the nature of the study to the participants, including the risks and benefits that could arise as a result of their participation, they were then given the consent form to read and encouraged to ask questions on areas that they didn't understand before signing the consent form. Interviews that lasted for 30-40 minutes commenced after the consent form was signed. The questions allowed the participants to reflect on their experience. After the interview both the research informant and the researcher agreed on when the next interview will be.

Nine (9) informants were interviewed, six (6) female, (3) male. At the time, the researcher had finished interviewing the 9th informant she had already reached the saturation point, and there was no need for further data collection.

The following steps, representing Colaizzi (1978) process for phenomenological data analysis were utilized: (1) Transcribing all the subjects' descriptions. In this part of the analysis process, participant narratives were transcribed from the audio-taped interviews held with each. According to Colaizzi's (1978) process, the narratives do not need to be transcribed verbatim, as long as the essence of what the participant was communicating is caught in the transcription. Individual transcriptions of the interview are then validated by the respective participant on the date the researcher and the informant would have agreed upon; (2) Extracting significant statements by leaving out statements that do not directly relate to the phenomenon under investigation. Colaizzi (1978) noted that any statements in the participants' narratives that relate directly to the phenomenon under investigation are considered significant. Significant statements are extracted from each of the narratives and numbered; (3) Creating formulated meanings: In this stage of analysis, Colaizzi (1978), recommends that the researcher attempts to formulate more general restatements or meanings for each significant statement extracted from the participant's narratives; (4) Aggregating formulated meanings into theme clusters: Colaizzi (1978) suggests that the researcher assign or organize formulated meanings into groups of similar type.

In other words, the formulated meanings are grouped into theme clusters; (5) Developing an exhaustive description. A comprehensive description is developed through a synthesis of all theme clusters and associated formulated meanings explicated by the researcher; (6) Researcher interpretative analysis of symbolic representations from the articulation of the symbolic representation (which occurred during the participant interview); (7) Identifying the fundamental structure of the phenomenon. The fundamental structure refers to 'the essence of the experiential phenomenon as it is revealed by explication' through a rigorous analysis of the exhaustive description of the phenomenon; (8) Returning to participants for validation. A follow-up appointment is made between the researcher and each participant for the purpose of validating the essence of the phenomenon with participants. Any alterations are made according to participant feedback to ensure their intended meaning is conveyed in the fundamental structure of the phenomenon. Integration of additional information provided by participants for inclusion into the final description of the phenomenon occurs at this point.

The researcher stopped gathering data once data saturation was reached, which was determined when themes and categories in the data become repetitive and redundant such that no new information could be obtained by further data collection (Polit & Beck, 2004).

Moral standards were maintained throughout the course of the study by putting careful attention to issues of recruitment, written consent, confidentiality, anonymity, potential vulnerability, and sensitivity. The purpose of the study was thoroughly explained; informants answered questions that they were comfortable with, without any element of force, fraud, deceit, duress, an ulterior form of constraint or coercion. Each informant was oriented to the research and informed that the interview will be in two sessions the second session will be after data transcription and was basically for validation. The informants were also informed about the benefits and risks of the study before being asked to sign the consent form.

It was possible that the informants could elicit mild psychological distress as the process of sharing their journey in raising an autistic child will bring to memory some memories they would rather avoid sharing. The informants were asked to take breaks between the interviews in case they became overwhelmed with sadness. Informants, whose distress level became intolerable, were referred to a psychologist. The informants benefited from this study in the sense that through sharing of their experiences and feelings they were able to examine themselves and accept their children with special needs. Through sharing, they gained insights into their feelings and how it affected their care to the autistic child. This helped them deal with their difficulties and learn to accept the challenges in taking care of a child with special needs.

To maintain anonymity, the researcher gave each informant a pseudo name for each informant to protect their identity. Only the researcher was able to access the recorded and the written information shared by the informant. The researcher was true to what they agreed with her research informants; that was to dispose properly of any data gathered after her final defense. Removal of data from the USB, memory drives, and written accounts were kept with utmost anonymity and confidentiality. All the data were completely deleted in all storage drives after the researcher had presented her final defense.

RESULTS AND DISCUSSIONS

Thematic Analysis

This section describes the findings of data generated from the respondents about social support system for children with autism. Experiences that were common to all the respondents, as well as distinctive experiences of individual respondents are also presented. Using content analysis, two primary themes were found to be most prominent from the data were; (1.) Need for Social Support System; (2.) Blessings amidst Difficulties.

Theme 1: Need for Social Support System

Having a child with a disability is challenging, the hardships that parents go through as they try to find meaning in their child's condition bring them close together (Lickenbrock, Ekas & Whitman, 2011). Parent's perception of the child's disorder determines marital adjustment; families that focus on positivity rather than negativity more social support is crucial during this time because it will help parents stick together (Lickenbrock, Ekas & Whitman, 2011)

For Havana, having a supportive husband helped her through her depression as seen in her response below:

"I have a very supportive and hardworking husband, who is helping me get through my depression and provides for our needs especially after I stopped working".

Cha like Havana was able to move on with the support from her husband.

"I have a very supportive husband who has been with me throughout the challenges and despite how hard it was for me to move on after my child's diagnosis, he became the shoulder to lean on" as verbalized by Cha".

Cris reported that their marriages became stronger due to facing challenges of ASD together.

"Having a special child has strengthened our relationship with my spouse, I feel more attracted to her now than I ever did, the bond between us even strengthen with trials" as verbalized by Cris .

Some families had members from the extended family come to help financially. Luda when asked about the positive and negative aspects of raising a child with autism replied by saying;

"Taking care of Gabe is expensive as compared to the other kids that the extended family come to help when I'm defeated here and there"

Yaya's (House helps) through their support in caring for the autistic child made it possible for couples spend time together. Cha stated that;

"We still have enough time for my husband as a couple; this has been possible for us since we have had good 'yayas' that have helped us care for Kim during our dates" (SS11).

Parents who spend time together are in a better position to deal with challenges, and their relationship becomes even stronger Santoso et al. (2015).

Parent support groups that emphasize sustaining couples' relationships during times of stress (rather than just focusing on their roles as parents) are beneficial for families with children with ASD. Support from family members and other people from the environment, the involvement of the father in the child care and understanding of the child's condition among extended family members is fundamental to mothers' resilience by easing their emotional and practical burdens Santoso *et al.* (2015).

Dida whose child with autism is 11 years had joined a support group. She says her circle of friends after diagnosis has widened to include parents with a child with autism.

"My circle of friends widened after my child was diagnosed with autism to include parents with autism, we have formed supportive groups, and they have helped me a lot regarding coping" as verbalized by Dida.

Joining a social support group will enable parents to share ideas with other parents with the same condition as theirs thus enabling them to increase in knowledge about the disorder and to pick up some of the positive attributes that have benefited other kids with the same condition as their child (Davis & Carter 2008).

Theme 2: Blessings amidst Difficulties

No matter how disheartened each parent was by their child's condition, there was still one reason to smile, that one attribute in their child that kept them going, the rose among the thorns that lit up their spirit whenever they looked at their child with autism. For Gutu, her son is a blessing from God, which alone kept her positive as seen in her statement below:

"I consider my child a blessing from God though the challenges are pressing I'm always positive" Gutu

Havana and Tim developed positive virtues such as endurance and patience. Tim like Gutu considers his child with autism as a gift from God as seen in their statements below:

"Endurance has become a virtue after raising my child with autism" as verbalized by Gutu

"My child has taught me to be patient, a virtue I would not have developed had I not been gifted with him" as verbalized by Tim

Dida was pleased by the idea that his son will always be there with her since he won't be involved in any relationship as seen in her response below:

"My son will be here to stay with me forever. Since he won't get married, he will forever remain mommy's boy" Dida chuckled

As the saying goes, every dark cloud has a silver lining all parents saw something positive in their child with autism. They said he was a blessing from God; they turned to God to teach to live one day at a time no matter how pressing the situation around was.

IMPLICATIONS AND RECOMMENDATION

Most parents in this study sought knowledge from the internet in regards to their child's condition rather than consulting the doctors that give the diagnosis to know more about the diagnosis. This indicated that no relationships were formed between the health care providers and the clients.

This study reinforces the need for more support for parents with a child with autism especially during the diagnosis and throughout visits to mental institutions when seeking therapy. Autism is a lifetime disorder that warrants lifetime intervention because change is continual. Lack of knowledge and understanding about autism, parents' attitudes on the disorder and misdiagnosis are the major reasons for delayed diagnosis.

Since this disorder does not choose who it affects, and any parent can be a victim, it is, therefore, important that everybody should be informed. Increasing awareness of this disorder is vital and of great benefit for parents and the society at large. Hospitals should print leaflets that highlight early detection and appropriate management of the disorder.

This research has indicated that strong family support system leads to positive coping; therefore nurses should offer continual support for parents with a child with autism when they visit any health care facility, this will help prevent anger build-up in parents protecting the child with autism from child abuse.

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