

Involvement of Grandmothers in Caring for Children with Autism in the Philippines: An Interpretative Phenomenological Analysis

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Arvin Kim A. Arnilla (PhD)

Aklan State University-Main Campus, Banga, Aklan, Philippines
arnilla_kim@asu.edu.ph

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Abstract – *This study looked into the lived experiences of Filipino grandmothers rearing children with autism (CWA) focusing particularly on the extent of their involvement. The study used Interpretative Phenomenological Analysis (IPA) through interview and storytelling of eight (8) Filipino grandmothers. Analysis of data generated three themes such as “I watch him every time his parents are out” (physical involvement), “I hope one day he’ll be okay” (emotional involvement) and “Financially, I gave whatever I have” (financial involvement). The study attempts to explain the extent of involvement of grandmothers in rearing children with autism across these dimensions. Physical involvement is bounded by physical strength, emotional involvement is bounded by self-restraint and financial involvement is bounded by financial capability. The caring and nurturing nature of Filipino grandmothers is translated to their physical, emotional and financial involvement in rearing their grandchildren from conception to adulthood. Filipino children with autism as described in this study had issues covering the broad categories of deficits in social communication and social interaction and restricted, repetitive patterns of behavior and interests. Given the atypicalities and the inherent impediments experienced by those in the lower socio-economic status, intervention programs can be created and implemented to address them.*

Keywords – *autism, rearing, Filipino grandmother, Interpretative Phenomenological Analysis*

INTRODUCTION

Autism is a lifelong neurodevelopmental disorder that exacts many physical, financial and socio-emotional tolls to parents. Studies conducted in the Philippines confirm the struggles of parents caring for children affected with this condition. [1] But unseen in the picture are the contributions made by grandparents in the process of rearing these children. This study assumed that the examination of their role and the extent of their involvement are necessary in effectively addressing the psychosocial needs of their grandchildren with autism.

In the Philippines, studies closely related to this present paper focused on the grandparental involvement in rearing typically-developing children. A recent survey confirmed some of the observations on caregiving role played by grandparents. It was observed that 27.1% of grandchildren co-reside with their grandmothers and 80.1% of them are below 6 years old. An overwhelming 78.0% of co-residing grandchildren received grandmothers' care. [2] The material and financial support extended to both their children and grandchildren make the grandparents a resource for the family. The assistance includes non-

material and non-monetary support to children like taking care of grandchildren, participating in household activities/ chores and acting as family advisers when members of the family are having problems. The inclusion of non-material and non-monetary support such as taking care of grandchildren, participating in household activities/chores and acting as family advisers when members of the family are having problems. Age, sex and education of grandparents were found to be important in supporting children. Age, sex and perceived health status were the variables having most influence to the support given to grandchildren/ household participation. Grandfathers are more likely to assist in economic aspects while grandmothers tend to assist in household matters. [3]

This is shown in the self-concept of grandmother as “someone who takes care of the grandchildren when the mother is not around.” [4] They acted as substitute caregivers when the mothers need to do some errands. They provided their grandchildren almost all of the caregiving roles attributed to the children's mother. Feeding was the most common activity grandmothers do for their grandchildren [5]. Although they perceived

this caregiving task as an obligation, they enjoyed giving affection to their grandchildren [6]. These sacrifices of grandmother were also reciprocated by the grandchildren. Del Rosario discovered that most children felt happy about the activities their grandmothers do for and with them [7]. In fact, children were negatively affected with their absence. Despite the increasing urbanization and modernization, the traditional filial duties and roles of grandmothers to their grandchildren live on. Evasco-Rellosa reported that grandmothers define discipline as a strict adherence and obedience to rules and as submission to authority. But as they grow older, their views on the discipline needed for particular behavior such as fighting, resisting orders, temper tantrums, aggressive behavior and messiness diminish [8].

In Philippine context, there is a dearth of published literatures as great majority is comprised of unpublished theses. These literatures qualify the Filipino grandparents as caring and nurturing individuals fulfilling various social roles in an intergenerational arrangement. To date, no phenomenological local studies on grandparenting children with autism seem to have been conducted.

OBJECTIVES OF THE STUDY

This paper delved into describing the role and extent of involvement of Filipino grandparents in rearing grandchildren with autism. It concentrated on each individual participant’s experience of the phenomenon.

Research Question: How do Filipino grandparents describe their role and extent of involvement in rearing grandchildren with autism?

Interview Questions

1. How do you describe your experience when your grandchild was born?

2. How did you react when you first learned that your grandchild has autism?
3. If you were to describe your role as grandparent to your grandchild with autism, what would you say? Prompt: *What word comes to mind, what images?*
4. How do you extend help in taking care of your grandchild with autism?

Prompts: *physiologic needs, sensorimotor needs, socio-emotional needs, cognitive needs, and communication needs?*

MATERIALS AND METHOD

The study used Interpretative Phenomenological Analysis [9] to describe the lived experiences of Filipino grandparents rearing children with autism. The research was conducted in three different provinces in the Philippines. The researcher contacted SPED centers and therapy centers for referrals. Generally, each grandparent-participant was informed by channels regarding the invitation for interview. The channels (SPED teacher, SPED Center employee and grandparent-participant themselves) made the initial explanation of the purpose of the interview days before the actual interview. When the prospective participants agreed, the channel contacted the researcher through mobile phone. The interviews were set either in homes or in the centers. Using purposive sampling, a total of eight grandmothers participated in this study with a median age of 60 years old, who willingly shared their stories for this study. Four of them completed elementary education, two finished high school and two graduated college. As regards occupation, majority of the participants were housewives with income coming from pension, allowance from their employed children and salary.

Table 1. Profile of the Grandparent-Participants

Participants	Age Range	Civil Status	Religious Affiliation	No. of Children	Educational Attainment	Occupation	Source/s of Income
Sarah	60-70	M	Christian	2	Elem.	Housewife/ Entrepreneur	Business
Martha	40-50	M	Christian	4	College	Housewife/ Entrepreneur	Business/ Allowance
Louise	50-60	M	Christian	3	HS	Housewife	Allowance
Mary	70-80	W	Christian	9	Elem.	Housewife	Pension
Agnes	60-70	M	Christian	6	Elem.	Housewife	Allowance
Marcella	40-50	M	Christian	5	HS	Housewife	Allowance
Adela	60-70	M	Christian	3	College	Retiree/ Educator	Pension/ Salary
Julia	70-80	W	Christian	6	Elem.	Retiree	Pension

There was one grandmother who retired from the government service and continues to be employed in the private sector. All participants had one grandchild with autism. The profile is shown in Table 1.

Table 2. Profile of the Grandchildren

Participants	No. of GCWA	Age	Gender of GCWA	Relationship w/ the CWA
Sarah	1	3	F	Paternal Grandmother
Martha	1	11	F	Maternal Grandmother
Louise	1	9	F	Maternal Grandmother
Mary	1	10	M	Paternal Grandmother
Agnes	1	7	M	Maternal Grandmother
Marcella	1	7	M	Maternal Grandmother
Adela	1	15	M	Maternal Grandmother
Julia	1	21	M	Paternal Grandmother

The profile of children with autism is shown in Table 2. During the actual interview, the researcher introduced himself and explained to them the purpose of the interview. He showed them the *Informed Consent Form for Qualitative Study* based on the template of the World Health Organization (WHO). He told them about its contents and implications regarding the subsequent activity. He also reminded them of their opportunity to withdraw from the interview at any point when they feel uncomfortable. He asked them to sign the informed consent form. A *Brief Biographical Questionnaire* was also used to record important personal details. Following rapport, an in-depth, semi-structure interview followed. All interviews were audio-recorded, transcribed verbatim.

Prior to analysis, a matrix containing the real names with the corresponding aliases was drawn up in order to conceal the identity of the grandparent-participants. The researcher would tediously look at this matrix every time he would attribute a quote.

Similarly, all identifying information in the discussion were removed to protect the identity and privacy of the participants.

The Interpretative Phenomenological Analysis (IPA) approach was chosen in generating the themes suited for the topic and the objectives set for this investigation. Manual transcription was completed and coding used the following steps: 1) *reading and reading*; 2) *initial noting*; 3) *developing emergent themes*; 4) *searching of connection across emergent themes*; 5) *moving to the next case*; and 6) *looking for patterns across cases*. [10]

Insights and comments on grandparents' involvement on the rearing of children with autism were clustered using hierarchical coding.

For the trustworthiness and coding accuracy, he disclosed the data set to two colleagues who were both qualitative researchers in the fields of communication and psychology. Both were independent of the research project. They reviewed the coding for one transcript and reviewed the themes/subthemes for the overall sample, providing general comments and suggestions. Further, a member of the research committee also reviewed the initial units of meaning codes for all data sets. Discrepancies were reviewed and consensus was obtained, agreeing on the final codes and the themes, subthemes, and categories. To validate the data analysis, the suggestions of Creswell regarding member check and external auditor were performed [11]. For member check, the researcher presented the findings to two participants who both agreed on the themes generated from the study. As regards external auditor, the researcher sought the expertise of a professor of qualitative research affiliated with Philippines' premier state university who is not familiar with the researcher. She was requested to conduct an audit of the data set and see how these were reflected on the discussion. All her observations, comments and suggestions were incorporated in this final paper.

Table 3. Codes and Themes

Codes	Themes
• <i>becoming a grandparent/ pride/ celebration/ fulfillment/ happiness/ having a grandchild/ same love for all grandchildren/ favoritism (girl)/ favoritism (due to condition)</i>	Emotional Involvement
• <i>hope for improvement (maturation)/ hope for recovery</i>	Emotional Involvement
• <i>absence of speech/ desperation on the inability to speak/ hope for improvement (speech)</i>	Emotional Involvement
• <i>discovery of the condition/ comparing with other children/ surprised</i>	Emotional Involvement
• <i>denial of the condition/ disbelief on the condition</i>	Emotional Involvement

Table 3 (cont). Codes and Themes

Codes	Themes
● <i>frustration/ disappointment/ helplessness/ frustration on society</i>	Emotional Involvement
● <i>understanding autism/ knowledge on autism/ limitation of understanding on autism</i>	Emotional Involvement
● <i>sadness due to deficit/ grandmother's love/ compassion/ strategy to cope with separation anxiety/ showing affection</i>	Emotional Involvement
● <i>hope for improvement (bathing)/ hope for improvement (toileting)</i>	Emotional Involvement
● <i>acceptance of the condition/ fatalism/ coping with the difficulty/ allowing their children to become parent/ substitute parent/ allowing the mother to become parent/ pity/ confusion/ aspiration/ pride on the better state of the grandchild</i>	Emotional Involvement
● <i>normalcy</i>	Emotional Involvement
● <i>sacrifice/ difficulty in rearing (behavior)/ difficulty in rearing (academics)/ difficulty in rearing (feeding) / difficulty in rearing (rituals)/ difficulty in rearing (a-d-l skills)/ difficulty in rearing (haircut) / health monitoring/ like my own child/ assisting the parent (feeding)/ assisting the parent (rearing)/ assisting the parent (watching the kid)/ role of grandparent/ giving advice to parents on education/ pampering the child/ caregiver role/ began to rear the child/ limitation in rearing (education)/ limitation in rearing (tutorial)/ limitation on the participation/ monitoring improvement</i>	Physical Involvement
● <i>difficulty in rearing (financial)/ assisting the parent (financially)/ assisting financially/ limitation on the assistance (financial)/ no economic assistance/ family support/ sibling support/ buying things for school</i>	Financial Involvement
● <i>difficulty in teaching (behavior)/ difficulty in teaching (at home)/ difficulty in teaching (classroom)/ difficulty in teaching (social skills)/ difficulty in teaching (academic skills)/</i>	Physical Involvement
● <i>general strategy in teaching/ strategy in teaching pre-academic skills/ strategy in teaching social skills/ strategy in behavior management/ strategy in teaching a-d-l skills/ strategy in develop motor skills/ taking to and picking from school/ strategy in monitoring academic achievement/ teaching at home</i>	Physical Involvement
● <i>strategy in teaching speech/ strategy in teaching writing</i>	Physical Involvement

Table 4. Themes

A. <i>“I watch him ever time his parents are out” (Physical Involvement)</i> recounts the physical hardships associated with rearing a child with autism. In most cases, grandparents took an assisting or supporting role to parent in taking care of the needs of children with autism. Yet both of them shared common difficulties in the process of rearing. These difficulties in physical involvement were punctuated by caregiving issues, atypical attributes of children with autism, health issues and mobility issues.
B. <i>“I hope one day he’ll be okey” (Emotional Involvement)</i> outlines the six emotions confronting grandparents when relating or dealing with their grandchildren with autism
C. <i>“Financially, I gave whatever I have” (Financial Involvement)</i> describes the material and monetary assistance extended by grandparents to parents of children with autism and to the grandchildren with autism themselves.

RESULTS AND DISCUSSION

The results of the study are summed up in this figure. It shows three themes generated from the interviews and storytelling. These are the following: *“I watch him ever time his parents are out”* (physical involvement), *“I hope one day he’ll be okey”* (emotional involvement) and *“Financially, I gave whatever I have”* (financial involvement). These dimensions of involvement come at varying extent.

Theme No. 1: *“I watch him every time his parents are out”*

Physical involvement entailed grandparent to actively demonstrate caregiving tasks so parents can mimic them for their children. This is particularly shown by first-time grandparents. Caregiving tasks involves feeding, bathing and watching them while

their parents were out of the house to work or perform other tasks. For instance, Martha detailed the sacrifices she did for her granddaughter while the mother went to school to work as a public high school teacher. *It feels like she’s my own child. That you bathe her. Then you bottle feed her. Even now, that her Mommy is tired from work and they sleep together, I go downstairs to check if her back is wet. If she has diapers. At times, she does not want diapers anymore. She’s grown up already. Then I’ll check if she has been fed. I’ll ask her Mommy if she was already fed. That’s it. I do it every night even if Angel is already grown up because she needs constant care.*

Similarly, Marcella shared that the caregiving tasks she did for his first-born grandson were the same activities she did for her own biological children. *“[I*

took care of him] like when my own children were small. I take care of him like the way I did to my children. Of course, preparing coffee, staying awake at night. Bathing. That's it. Having him drink milk. Then, bringing him outside to socialize with others."

Caregiving issues like activities of daily living (A-D-L) equally confronted grandparents. Louise related her struggles in feeding her 11 – year old granddaughter, Mia. She took over the primary caregiving responsibility to her granddaughter when the family lost the household helper who assisted them. It also forced her to stop selling at the public market. "There are times you have to pull her by the hair. Hold her nape...feed her because she doesn't want to eat at times. Now, if there's no gadget, she won't eat. She wants to hold it. She's playing [with it]."

Louise also reported that Mia is not toilet-trained. In fact, during the interview, she was ashamed for the smell of urine in the receiving area of the house. Bathing was another challenge for her. Mia would at times proceed to the bathroom located at the second floor of the house and open the shower and stand under it without removing her clothes. Louise would then rush to the second floor to assist her complete the task. The humid temperature is also making another headache for Louise. Mia would just remove her clothes and go naked while roaming inside the house. It raised alarm for her part as Mia is already an adolescent who would soon experience menstruation, therefore, vulnerable to sexual abuses. As part of their protective stance, they do not allow non-relative males to live with them in the house.

Mary is sometimes requested by her daughter-in-law to watch Jun. Sometimes it was Jun who "visits" her. Being the most senior among the participants, she calls Jun whenever the latter goes out of the house and moves towards the gate. The house is situated along a busy street. She also does the same when Jun goes to neighbor's house. She is afraid her grandson could destroy something.

The aberrant behaviors of children with autism posed tremendous challenges to grandparents. For the aging ones, they could not contain the aggressive behavior of the child. As such, they would take distance and simply leave the matter to the child's parents who are more physically able. During shopping, for instance, temper tantrum occurred when the child's demands were not heeded to.

When I pressed about Agnes it, she shared a typical scene inside a mall with her daughter, her grandson with autism and herself. She described her grandson as

"restless," and "making a scene." "Sometimes, if he wants something, and you do not give it, he'll make a scene. Sometimes, we ask the guard to carry him ... We could not stop him."

According to Bauzon & Bauzon, the attempt of grandparents to pacify children with autism who threw tantrums in public places such as malls or shopping centers is reminiscent of the findings of who reported that Filipinos tend to control aggressive behavior in children. [12] This attempt of controlling behavior of children, as experienced by Mary was reported by Evasco-Rellosa who claimed that grandmothers define discipline as a strict adherence and obedience to rules and submission to authority [13]. This action of grandparents could also be related to belief that children do not have a "mind of their own" [14] which results to constant reminding of "what to do and what not to do" [15].

The physical involvement of grandparents is not only limited to caregiving activities but extends to teaching their grandchildren at home. Of course, the atypical attributes associated with autism make this involvement a perplexing experience. While at home, grandparents have learned to adopt strategies to teach their grandchildren various skills particularly aimed at addressing the deficits. For speech, Marcella bought a video compact disk (VCD) containing nursery songs and she kept on playing this VCD with the end goal of improving the speech of her grandson, Miguel. Modeling the correct way of speech was also taken into account. Likewise, they have realized not to use "baby talk". This is true in the case of Agnes. She's taking all opportunities to teach her grandson the alphabet and ultimately, speech. And this includes bathing time.

Teaching these children academic skills at home include the teaching the alphabet through drill method. Grandparents also assist when the child is doing the coloring books. As a trained SPED teacher, Adela came up and implemented an intervention program centered on his grandson's interest to develop his speech. Adela related: "We tried to use Barney as our intervention program for him. My daughter and I... so it still we were able to let him talk by singing with him. Then he will add word, whatever the end word."

Adela's extent of involvement in the academic activities of her grandson Robin is determined by high educational attainment and trainings in SPED. In addition, Adela put labels on objects around the house to associate names with tangible objects. Grandparents used drill method in teaching speech to their grandchildren. Yet some grandparents reported that

their grandchildren resisted on their attempts to teach them at home.

Julia participated in the academic life of Paolo by answering the latter's queries about his lessons in school. She also taught him to write at home. Grandparents used modeling to teach social skills. They demonstrated hugging, kissing and other forms of affection. In my visit to Louise's house for the interview, her grandson fetched Mia from the second floor of the house. Louise then prompted her granddaughter to get my hand and kiss it. Mia got my hand and put it on her forehead. In my part, I said "*God bless you*" as a standard Filipino response to the gesture. Martha also taught Angel (her granddaughter) similar actions. She described the process as: "*We teach her how to hug. We teach her how to kiss.*"

They also disclosed that they monitor activities closely when the child arrives from school or from the therapy centers. The grandparents also served as the connection between the school and the children's parents. Martha shared that her granddaughter's teacher freely relayed to her the latter's behavior at school which she also reported to Angel's mother. "*When there's an assignment, 'Mommy, Angel has this. Angel ... refuses to do the task.' Then we do the puzzle, beads. She also works on them. Then she just refuses to finish it. Then I also share this to her mommy.*"

Marcella, on her part, reminded her daughter of the regular and upcoming school activities which her child must participate. They also monitored the school activities in order to reinforce what was done in school. Adela shared: "*I always try to ask the program from his school and try to check it out. And try to find out how he is doing. And there is no problem that has been given to us. Only that he is very shy. Those are the things that he was observed to be shy. However, I told the teacher to let him participate in anyway.*"

Having an active physical involvement in the education of their grandchildren led some of these grandparents to observe on the improvements SPED apparently gave their grandchildren. Grandparents whose grandchildren attended public SPED centers reported that the quality of instruction suffers tremendously. They attributed this to the number of pupils and few teachers. Time allotted for each child is limited to one hour or less. The activity and attention given to the child were equally very limited. No regular feedback on the development of the child was made.

A grandmother frankly stated that when her granddaughter's SPED teacher focused on her, her granddaughter had learned several pre-academic and A-

D-L skills. However, the reality in public SPED center where many children compete for the teacher's attention reduced the opportunity for interaction between the CWA and the SPED teacher resulting to pupils being sidetracked- bound to coloring activities when in school or reduce the number of days in school. The lamentable condition is verified by Yap & Adorio [16] who reported that access to SPED service is related to size of enrollment of children with special needs. In this case, too many pupils reduce the opportunity to address their needs individually. On the other hand, grandparents whose grandchildren attended private SPED centers recounted marked improvements on their grandchildren across developmental areas. Aside from the expensive regular school where they were mainstreamed, they had also undertaken intervention programs like speech therapy, occupational therapy sessions and had one-on-one academic tutorials in privately-owned centers.

The grandparents were also involved in health monitoring. A number of grandparents reported that their grandchildren were frequently sick when they were still a lot younger. Marcella related that when Miguel was a child, he was sick almost every week. Sarah likewise described Princess as a whiner, bilious and had frequent seizures. Louise, on the other hand, shared that Mia had frequent nose bleeding when she was between 2-3 years old. Julia likewise recalled that Paolo had asthma attacks when he was young.

Children born of poor parents are at a disadvantaged in many ways. Mobility is one. Grandparents disclosed that coming to school requires a private transportation. Martha whose family lived in a subdivision finds transportation as a big challenge. To bring her granddaughter to school and to the therapy center requires them to walk from their house to the public transport terminal and back. "*The 10:00-11:00 schedule at school is a challenge. We have to rest at the Annex [high school] at her Mommy's classroom at 12:00, no at 11:00-12:00. We walk to school and this makes her sick because of the travel to the therapy. Her therapy is slated at 1:00-2:00. She always catches cold and cough.*" Having anticipated mobility as a problem, Lucia's family bought a tricycle take and pick Mia from home and to school. Mia's father is an overseas Filipino worker.

The preceding descriptions affirm the three types of grandparental roles as explained by Reyes & Baviera [17]. First, grandparents volunteered their services which described Agnes. Second, their services were requested. Mary and Adela were perfect examples.

Third, they assumed the responsibility which was portrayed by Sarah, Martha, Louise, Marcella, Adela and Julia.

Despite these convoluting issues, grandparents were willing to perform caregiving tasks. As explained by Martha, the sacrifices she made in rearing her granddaughter were made out of love. She exclaimed: “*We have loved her even more because she needs understanding. And then one should not hide children like her, right? You should be proud even if your granddaughter is like that, right?*”

The grandparents expressed fulfillment on performing caregiving tasks ratifying the conclusion made by Suico & Gatbonton [18]. Maternal grandmothers acting as surrogate parents for children with autism corroborated the result of presented by Sorita [19]. Caregiving tasks included baby-sitting, feeding, playing with the child, taking and picking the child up from school [20].

Physical involvement of grandparents is bounded by physical strength. Aging grandparents like Agnes, for example, openly spoke of her inability pacify her grandchild when the latter had temper tantrum. “*Yes. I can't do it. He's strong.*” For the well-off families, household helpers would assist in caregiving tasks. This is true to Adela, Agnes and Louise shared this experience. Assisting the parents of the child with autism is a family affair. Apart from grandparents, siblings of the parents of the children with autism also helped. The grandchildren of Martha, Mary, and Marcella belonged to this category.

This result further confirms the conclusion found in earlier studies that age, sex, and education of grandparents was found to be important in supporting children. As grandparents advance in age, they become weaker. They could not participate in tasks requiring physical energy like controlling the behavioral outburst of their grandchild. In this study, it is also shown that grandmothers tend to perform more caregiving tasks compared to grandfathers. Lastly, educational attainment impacts grandparents' ability to assist in teaching their grandchild.

Theme No. 2: “*I hope one day he'll be okey*”

The emotional involvement confronting grandparents of children with autism is wrapped up in this meaningful quote. Becoming a grandparent, and subsequently, a grandparent to child with autism occasioned an interplay of various emotions. For this theme, six subthemes emerged. These are the following: (a) *Happiness* talks about the joy of

becoming a grandparent; (b) *Confusion* relates the state of bewilderment as the grandchild deviated from the norm; (c) *Frustration* narrates exasperation over the alarming condition of the child; (d) *Denial* recounts the doubting the diagnosis; (e) *Sadness* recited the pain of having a “special” member in the family; and (f) *Acceptance* describes the desire to assist the child attain normalcy.

Happiness. Becoming a grandparent brought joy to the participants especially to those who became grandparents for the first time. This could be seen on the events describing delivery. While the soon-to-be-mother endures the pain of labor, the entire family is excited in preparing for the things she needs. This is true to deliveries done at the hospital and at home. I have learned that joy was even sweeter for those who had grandson as “*he ensured the continuity of the family lineage*” (Marcella). This feeling highlighted Filipinos' emphasis on boy-child as agent to keep the ancestry existing. Grandparents would like to experience second wave of parenting as demonstrated in the case of Julia. As her children were all grown-up, she was excited to take care of her grandson, Paolo. Grandmothers openly spoke of their desire and the ensuing fulfillment when they got a granddaughter. Agnes conveyed that among her grandchildren, apart from her granddaughter, she would favor her grandson with autism because of his condition. This is a confirmation of studies which claimed that children bring out joy, happiness, fulfillment to grandparents [21].

Confusion. Almost all of the grandparents had neither experienced autism nor heard about it. So they all expected a typically developing child to finally join the family. Most of them were also first-time grandparents. Still experiencing the thrill of becoming a grandparent, the celebration would gradually be replaced by confusion as the child manifested significant deficits and excesses contrary to the expectations of the family. Nobody in the family was prepared for the birth of a child with autism. Participants' wondering about their grandchildren's condition came in gradually. The members of the household noticed the deviation from the expected/typical pattern of development. These observed deficits and excesses were atypical of their own children and/or other children around them. Deficits were characterized by lack/diminishing speech and lack of attention. Excesses accounted for restlessness, rituals, tantrums and fixation to objects. This is also speech deficit as in the case of Agnes'

grandson. In terms of attention, Julia spoke of her grandson who would not look back when his name was called and would not even look at people. All these observations were summed up by Martha, a first-time grandmother. She described her granddaughter in these words: *"We've detected her because for more than two years, she's not talking. She had no focus when you call her. She's very restless."*

Grandparents tend to compare the development of their grandchildren with their own children, grandchildren and their neighbors' children. The comparison became the basis for suspicion and further confusion. Martha was a mother to four typically developed children. In making the comparison, she reminisced her experience when her eldest son was growing up. Using this experience as basis, she claimed: *"I didn't have any child who learned to walk late because my eldest [child] walked when he was 7 months"*

Frustration. Along with the parents, the grandparents were also frustrated over the alarming condition of children. The feeling of pity sensed by the participants were associated with the child's handicap and his "being different" from other children. Being different from other children drew frustration for grandparents. Marcella, a mother to five children, described her granddaughter in a frustrating tone. She lamented: *"She's not socializing with us, with other people. I've noticed he's different. He's not like other children. He has a world of his own. His words are different."*

On the other hand, Sarah was a mother to two grown up young men. Her family lived in an area where children were of no shortage. With the kind of community she lived in, she could not help but notice and compare their development to her own granddaughter. She claimed: *"I have observed my children and the other children around. That before they reach one-year old, they can already utter 'mama' 'papa.' They can already mumble words. We wondered why she could not mutter 'mama' and 'papa.' I'm envious because child her age can already speak well."*

Agnes spoke of an incident when she scolded Lawrence's older brother who made fun of him. She spoke: *"If his older brother makes fun of him, we scold him. 'You should be patient with your brother. And not like that. You're normal while he's not. You should pity him.'"*

On the part of Louise, she reminds the older sister and a male cousin of Angel to help out in taking care of

the latter when primary caregivers are gone. The "Tagasalo" Theory [22] and "Pagdadala Syndrome" [23] operate in this reminder of Louise. Typical or regular siblings are obliged to takeover in caregiving tasks. To a certain extent, Arcadio's conclusion also plays up as Angel's regular adolescent sibling are expected, relied on, depend and trusted by parents with caregiving duties [24].

Denial. They never believed their grandchildren had autism because it did not manifest on the physical features. Despite the disturbing signs of delays, the participants still consoled themselves with positive and hopeful thoughts. In fact, one grandmother emphasized that her granddaughter was able to walk without assistance at the age of two. Giving these children time to catch up with peers became apparent in the description given by Mary: *"Why could he not speak? I wanted to believe that he could speak when he grew a little bit older. We, parents do not expect our children to speak right away. Sometimes normal children would utter words. Is it not until they reach one-year old? But when he reached one-year old, he could not say anything."*

Most grandparents would not readily accept the diagnosis. The children seemed "normal" at birth. And no one in the family has had autism. Also they used the physical attributes of the child to claim that he is a typically developing child. Louise described: *"He's not that obvious when he was born. He's normal. We did not even notice it."* Taking cue from the normal physical appearance of the child, grandparents expected for normal development. Mary said: *"You could not notice any deficit on him. He's still normal. Even if you look at him, he doesn't have any handicap."* In the case of Agnes, she claimed her grandson would recover from autism soon as she would repeatedly say *"It's nearing."*

Sadness. Agnes whose daughter married a seafarer had lived with them when the husband and wife had their first-born. She boasted of having taken care of a number of successful wards. Yet she could not contain her pity on her grandson. She said: *"It's a pity. His good looks are a loss. He's handsome."* The desire to have a granddaughter was trampled by the child's condition and it saddens Sarah. This feeling led her to say this statement in a depressed tone: *"She's the only granddaughter I got."* Sarah explained the feeling pity on the deficit shown by her granddaughter. She said: *"As a grandmother, of course, I am saddened because she was like that. And we want her to be normal. Of course, we pity her because she's different from other"*

children. That she's like that. And her inability to speak makes her cry. Of course, it makes one sad as she could not say what she wants to tell you. You cannot understand her. We just pacify her. Of course, we really pity her."

The participants voiced out their helplessness while facing the condition rummaging their grandchildren. Louise asked: "What will happen to her when we're gone". And this was echoed by Martha, too: "What then? Of course, I'm old." For her part, Mary emphasized the child's inability to cope with social requirements by saying: "What will happen to the child as he's like that?" Sarah asked: "Is there a hope for that?"

Diagnosis of autism was not readily accepted by most grandparents. With the exception of Adela, the word "autism" sounded new to most grandparents. The generic term of "special child" was used to explain the condition to one grandmother. The stigma attached to the term brought sadness to discomfort to her. "When we brought him... when her mom brought him to the doctor, of course, we could not accept [the diagnosis]. We actually cried about his condition. In fact, when my children knew about it, they also cried. We all cried. He's different, he's special. My grandson is special. That was something unacceptable. It hurts. The doctor said that my grandson is special. It really hurts us." (Marcella).

When I asked about her understanding of "special child," she associated it to an "abnormal" and "malnourished" child. Grandparents can tolerate the behavioral excesses of their grandchildren but not the deficits. They can accept their grandchildren's "restlessness" (excess) than "delayed or lack of speech" (deficit). Tremendous emotional challenge is also a common experience by grandparents accompanying their granddaughter in public areas. Martha recalled a painful experience while commuting from the house to school onboard a public transport. "In fact, it's really difficult. It's difficult to travel. Well, Angel is a lot better now. At first, I really cried on a jeepney because she grabbed the sunglasses of a woman. She's a little bit conceited. Then, she said hurtful words. I was not really ashamed to cry on the jeepney. I told her, "The child didn't mean it." And she said a mouthful. When we arrived home, I shared them the experience. They advised me not to mind it. I told them it's really hurting. They do not understand the situation of the child... Then I told her, 'Baby, don't do it, Baby.' She was simply looking at me why I was crying. I did not wail. My tears just roll knowing that there are still

people who could not understand despite their age."

Acceptance. Finally, grandparents had learned to accept the condition of their grandchildren. Because of the condition, they realized that their grandchildren would need lifelong assistance from caregivers. According to them, it is a sacrifice because the child is God-given and they've learned to love the child. Despite the condition, grandparents have ways to look for the points of pride.

Grandparents reported that children who had undertaken therapy session had improved significantly in their communication, cognition, A-D-L skills and behavior. Other participants recognized maturation as a factor for the startling improvements. As they have witnessed marked improvements in their grandchildren, most of them wanted their grandchildren to function like typically developing peers.

Marcella's aspiration for her grandson was deeply rooted on their socio-economic condition. At the time of the interview, their house was subject for demolition because it was affected by expansion of the highway. Hence, when I was asked for her aspiration for her grandson, her response was: "I want him to work as an engineer. Then work abroad. Get married at 27. He could have a house and lot. That can be called his own. Have a good-paying job." Marcella's desire to make her grandson live independently like typical children is felt in these words.

Adela who was an experienced SPED teacher counseled her daughter on the attitude that they should have for her grandson. She recalled: "I always have to talk to my daughter telling them about it. You must have to accept it. I am telling them, there's still hope for this. Although I said it is life-long I am not limiting what he can do but let's try our best to give what is due him."

On the part of Louise, he turns to special education to instill improvement on her granddaughter. She said: "She could not be here all the time because she's not seeing anything. There are times that she'll cry. She likes to go out. Take the tricycle. She would get shirt of Daddy or the key. Then she'll give it."

These statements of Adela and Louise are exceptions to what Tabuga [25] claims regarding Filipino families' desire to keep a child with special needs at home for protection and care. Martha already thought of a possible option for her granddaughter. Sad but realistic, she bared the plan of the local government unit which could potentially benefit her granddaughter. She said: "I pray that the mayor's proposal be realized. She proposed for the establishment of an institution to

house the special children, the PWDs.”

This also discovered that grandparents were particular of the future of the children with autism. One strategy is to pass on the responsibility to the typically developing sibling after the present caregivers die. It merely confirms Arcadio's findings [26].

As a whole, Liwag's findings of sadness and disbelief/denial was confirmed [27]. However, the current study discerned other emotions not included in her report like happiness, confusion, frustration and acceptance. In contrast to previously cited research, the subjects were parents of children with autism while the subjects of the present research were grandparents. The grandmothers were emotionally affected by the condition of their grandchildren. The stages described their emotional journey. Even so, self-restraint explains the limits of the role they play as they recognize their children's primary parenting role. The statements made by Martha and Marcella were very telling. *“Though I'm the grandmother, though I give my best to him, the mother can do better, right?”* Marcella shared the same insight of recognizing the primary role of the parent, particularly that of the mother: *“First and foremost, I call the mother. Of course, she's the mother. I am just the grandmother.”*

Theme No. 3: “Financially, I gave whatever I have.”

This quote concludes the material and monetary assistance extended by grandparents to parents of children with autism and to the grandchildren with autism themselves. The extent of involvement of grandparents in rearing their grandchildren is likewise prominently shown in financial issues. Grandparents provide material and financial assistance to their grandchildren through children or directly to their grandchildren. The overarching theme can be summarized in the phrase “whenever I can.” Most parents of the child with autism were capable of spending for the needs of the child. Some parents opted to live within their means. As such, most grandparents would only bother to contribute financially when requested to.

Adela, for example, whose son-in-law was employed as seafarer can well-provide for the financial needs of the family. She described the situation in these words: *“... financially I gave whatever I have. But the financial aspect is done by his parents because the father can provide.”*

Mary, who has nine children, shared the same experience with his son and daughter-in-law. *“One is if I can extend help to them, I help them because they*

need something. And the parents are there. If they lack something, then they go to me. That's the time I help them. Of course, they do not depend on me that I will lead them. Simply put, if they need something, that's the time they speak to me. Then that's the time I help them.”

In the case of Sarah, she bought clothes and gave allowance to her granddaughter through the parents. Buying clothes for the granddaughter is resonant of Medina's report [28]. As regards extent of financial involvement, Mary describes a circumstance that prompted her to extend financial help to her children's family. Her comment was: *“When someone is sick and needs to consult with a doctor and when they lack money, I help them. As for the daily sustenance and they lack for it and I can provide, I give them.”*

Sarah shared the same concept: *“Whatever is lacking, I provide them. I do the follow up. Even in caregiving tasks, Sarah insisted on her assisting role as a grandmother.”*

This involvement of grandparents made them a resource for the family because of the material and financial support they extended to both children and grandchildren [29]. This was manifested by grandparents who have sources of income like Adela, Mary, Julia, Sarah, and Marcella. Moreover, financial involvement by grandparents is highlighted at the time child needed to be seen by professionals specifically developmental pediatrician. This was manifested in the experience of parents with limited financial resources. Some of the grandparents commented that financial constraints hindered parents to bring their children to specialist for evaluation at the earliest time. Financial issues haunt families with special children [30]. Martha, for example, talked about a situation prior to her Angel's diagnosis. She narrated that, *“The mommy was not yet permanent in her work [not a regular employee]. So it's a financial [issue]. Also I still have a fourth year college, no, third year student then, John, my youngest son. So we're really hard-up.”*

This does not mean, however, parents of children with autism living in the rural areas are taking the issue sitting down. These parents actively participated in information gathering activities relating to special needs and special needs children to respond better to the needs of their children. Sarah shared that her son and daughter-in-law sought professional opinion to improve her granddaughter's condition. *“Because [the parents] are asking around for their daughter. As to where could they avail of a better service.”*

The grandparents also took notice of the long wait

before the child can finally receive formal diagnosis. The shortage of developmental pediatricians practicing in the rural to less urbanized areas was another reason cited by these grandparents. And looking for a developmental pediatrician in other areas was not an option due to limited funds. Martha complained that due to the sheer number of clients lining up for evaluation at the clinic of a private developmental pediatrician, the schedule of her granddaughter's evaluation was moved several times. Mary, on the other hand, shared that her son and daughter-in-law braved the four-hour land travel to the regional center to take their son for evaluation by the lone developmental pediatrician on the island. According to Durban, private SPED school and centers congregate in urban area where the paying clientele are located [31].

CONCLUSION

The involvement of grandparents on the day-to-day routine of their grandchildren with autism is summed up in three dimensions such as the following: a) *Physical Involvement* which recounts the physical hardships associated with rearing a child with autism; b) *Emotional Involvement* which states the emotional issues confronting grandparents of children with autism; and c) *Financial Involvement* which shows the material and monetary assistance extended by grandparents to parents of children with autism and to the grandchildren with autism themselves. While all of the grandmothers demonstrated continuous service to their children and grandchildren, their involvement across the three dimensions is limited by a number of issues. Indeed, the stories of grandparents told in this study merely corroborate the current literatures attesting to the caring and nurturing nature of the Filipino grandmothers. However, this study clearly delineates the involvement of grandmothers in rearing a child with autism. To reiterate, physical involvement is bounded by physical strength, emotional involvement is bounded by self-restraint and financial involvement is bounded by financial capability. The caring and nurturing nature of Filipino grandmothers is translated to their physical, emotional and financial involvement in rearing their grandchildren from conception to adulthood.

This research established that the involvement of grandmothers is relevant, if not entirely important, in the daily lives of parents and the children with autism. From the basics of caregiving needs up to transitions to adult life, grandmothers and grandparents as a whole excellent resource to tap.

Lastly, this study focused on the Filipino grandmothers of children with autism using the Interpretative Phenomenological Analysis. As such, the next study may cover grandparents of children with other conditions or impairments and may employ quantitative approaches or mixed methods.

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