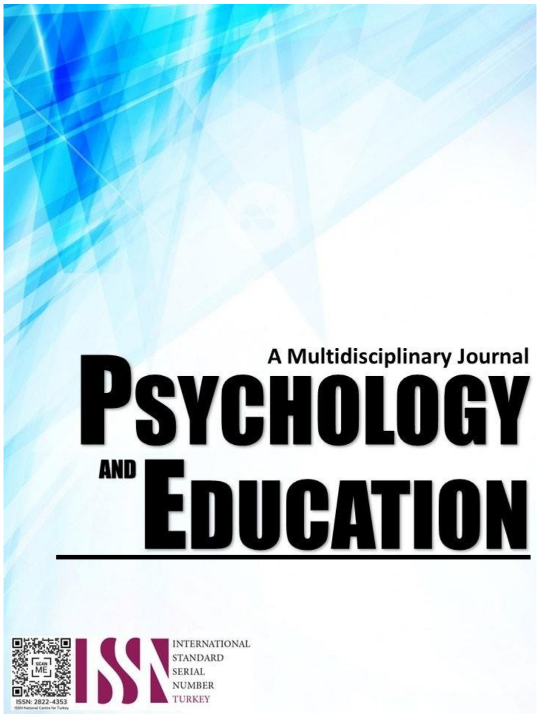
THE LIVED EXPERIENCES OF CAREGIVING PARENTS OF CHILDREN WITH AUTISM WHO SEEK INTERVENTIONS FOR THEIR CHILD



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Research Article

The Lived Experiences of Caregiving Parents of Children with Autism who Seek Interventions for their Child

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Abstract

In the last few years, there is a worldwide rapid increase in prevalence rate of parents having children who are diagnosed with autism. Within the literature, no single intervention or approach would assist all the children with autism, because of its variation in challenging characteristic from one child to another. The objective of this research was to explore an in-depth understanding of the lived experiences of six caregiving parents of children with autism who seek intervention programs for their child, how they make sense of their experiences, their challenges, and motivation using Interpretative Phenomenological Analysis (IPA). During the cross analysis, the following themes emerged. Process of Seeking for Intervention Program have three phases: the pre-seeking phase, actual seeking phase, and securing an intervention phase; Sense Making Process of Parents are Therapy as Integral and Therapy as Specialist-Guided; Parental Struggles in Therapy includes Time Management, Therapy Expenses, Therapy-Client Match, and Therapy Location Proximity; and the Contributing Factors to Parents' Motivation are Parental Love, Parental Responsibilities, Therapy Progress, and Hopeful Outcomes. Parents realizes how important therapy as part of the treatment process, and how it must be continued. They are aware that whatever decisions they would hold would greatly affect their child's progress or improvement. Finally, health care professionals in this field are encourage to enhance their knowledge, skills, and be updated with the necessary information about autism, because parents are highly dependent on them as their partners in their therapeutic journey.

Keywords: *lived experiences, caregiving parents, autism, intervention programs*

Introduction

In the last few years, there is a worldwide rapid increase in prevalence rate of parents having children who are diagnosed with autism (Adak & Halder, 2017). It is estimated that there is 1 in 160 children has ASD worldwide according to Mayada et al. (2012 as cited in World Health Organization, 2021). Across studies, this average figure can substantially vary. There are even higher figures reported in some well-controlled studies. Moreover, many low-and-middle-income countries prevalence are still unknown. In the Philippines, according to Dr. Borromeo of Autism Speak Foundation the estimated prevalence of individuals with autism in 2008 ranges from half a million to a million at present; although the figures should not be generalized because some areas in the Philippines were not covered (The Philippine Star, 2014).

According to Individuals with Disabilities and Education Improvement Act (IDEA), autism is a pervasive developmental disorder characterized by difficulties in verbal communication or the ability to express oneself through sound or words; social interaction or showing reaction to people around us like maintaining eye contact while speaking with them; and struggles with sudden change of routines. Other children may exhibit repetitive or stereotypical behaviors like body rocking; a strong need for sensory stimulations or activities that involves our senses, and learning difficulties (Hardman et al., 2014).

Raising a child is a challenging task that entails a huge amount of effort for parents, especially for those who have a child diagnosed with autism. While living almost independently for autism individuals can be possible, others are still in need of substantial support due to their severe disabilities. Several researchers have shown various effects of having children with autism in the family members such as psychological stress and distress (Al-Dujaili & Al-Mossawy, 2017; Fido & Al Saad, 2013) , poor psychological well-being (Zaki & Moawad, 2016), increased depression/anxiety (Rezendes & Scarpa, 2011) and problems with combining care with other daily activities (Hoefman et al., 2014).

In order to address the child's concern, parents who have a child with autism go through a process of accepting the diagnosis of their child and even seeking numerous intervention programs prior to diagnosis in order to cope with their child's condition (Gentles et al., 2019) They are confronted with a volume of information about autism available in the internet and other various sources (Grant et al., 2015). Moreover, they feel restless in the pursuit of continuously trying to find the most effective and suitable intervention for their children in the hope that with the right kind of services, their child will eventually live a normal life (Silverman & Brosco, 2007).

Considering the distinctive cases of each child with autism, various psychosocial interventions which are based on behavioral and educational approaches are also available for their needs, some of the most widely used and has evidence-based result includes: ABA Therapy, Denver Early Start Model, Floortime Model, and Pivotal Treatment.

The most common intervention and widely used for children with autism is the Applied Behavior Analysis or ABA Therapy. This therapy was derived from Behavioral Analysis that focuses on the study of behavior which applies the principles of learning and motivation. Alternatively, the Early Denver Start Model (ESDM) was based on the Denver Model, which is applied to older children with Autism Spectrum Disorder. Geraldine Dawson, Ph.D and Sally Rogers, PhD developed this early version which applies to children aging 1to 4 years old. It targets social interaction, integrated skill sets, and forming personal relationship which are the areas are where children are having difficulties (Applied Behavioral Analysis Program Guide, n.d.).

Next, Floortime intervention is an approach that can be facilitated by specialist, parents or any member of the family in order to maximize the developmental growth of the child. It's an approach that encourages children to young adults to communicate and responds by independent thinking or to find ways to solve the task rather than provide immediate answer to questions (The Floortime Center, n.d.).

On a personal note, the researcher observed numerous parents of children with autism in the center undergoing interventions or therapy programs one after the other. This observation sparked the researcher's curiosity as why parents are bombarding their child with various therapeutic approach, and still seeks other supplementary programs. Moreover, Numerous studies have been previously conducted to study various effects of raising children with autism on family functioning (Pisula & Porębowicz-Do¨rsmann, 2017; Zuckerman et al., 2014; Howell et al., 2015; Mohammadi & Zarafshan, 2014); psychological stress and distress (Al-Dujaili & Al-Mossawy, 2017; Fido & Al Saad, 2013); poor psychological well-being (Zaki & Moawad, 2016), increased depression/anxiety (Rezendes & Scarpa, 2011) and problems with combining care with other daily activities (Hoefman et al., 2014).

Recently, researches have focused heavily on the efficacy of intervention programs for children (Weitlauf et al., 2014; Romanczyk et al., 2014), Specifically, pragmatic language interventions (Parsons et al., 2017), sensory integration interventions (Pfeiffer et al., 2011), and exercise interventions (Chow & Tong, 2015).

Literature also focuses more on the totally of actual lived experience of parents just like in the researches of Abear et al., 2017; Celia et al, 2019; Corcoran et al., 2015; Tokatly et al., 2021 and usually emphasizes on the diagnostic process only (Makino et al, 2021).

Alternatively, a more specific experience of parents who have a child with Autism and how they make sense of their experiences amidst the constant search for interventions for their child can be studied in an in-depth manner to address the gap in literature.

Through an in depth understanding of the way in which caregiving parents make sense of their experiences as they live with the condition of the child, specifically in searching for intervention program for them; autism experts and related specialist in the field can come up with an approach that would shed light and aid other parents who are challenged by their child's condition. These expert's approach would be based from the shared experiences of the parents who are experiencing the similar situation.

Finally, Pivotal Response Treatment (PRT) targets developmental areas which are crucial to individual. It is a play-based method that was established in the year 1970 by Dr. Robert and Lynn Koegel at the University of California, Santa Barbara (UCSB) (Applied Behavioral Analysis Program Guide, n.d.).

Other therapy such as Occupational Therapy are being utilized to help children become independent in performing daily tasks such as taking a bath, eating, brushing and relating to people. While Speech Therapy aids in children with ASD to engage and improve their communication skills. Incorporating interpersonal skills training to children with ASD is a must skill in order to socialize with others through engaging in a conversation as well as problem solving skills (Center for Disease Control and Prevention, 2019).

Some dietary approaches were also developed to treat ASD symptoms, these includes removing certain food in a child's diet (e.g glutein or casein) and adding vitamins and minerals. Dietary treatment is being utilized due to the belief that the cause of autism is certain allergen in food or mineral and vitamin deficiency. While there is no medical cure to treat ASD, medications can help ASD individuals function better by alleviating its behavioral symptoms such as excessive amount of energy, difficulty focusing, and extreme worry (Center for Disease Control and Prevention, 2019).

Within the literature, no single psychosocial intervention or approach would assist all the children with autism, because of its variation in challenging characteristic from one child to another, which in effect make it more challenging for both parents and professionals in finding the best fit intervention for a particular child's concern (Ross & Salah, 2016). Similarly, according to Matson et.al (2013 as cited in Weston et al., 2016), there is a lack of substantial results regarding the efficacy of therapy and treatment for children with autism. Therefore, deciding what particular intervention would be highly beneficial for the child is a challenge to parents. Nevertheless, in spite of the limited empirical evidences supporting psychosocial interventions, parents still gain more confidence and hope through being familiar and knowledgeable about their child's condition amidst the frequent trial and error approach in choosing the best fitted intervention for their child (Grant et al., 2015).

Research Questions

This study focused on exploring the experiences of caregiving parents of children with autism who seek intervention programs for their children. Specifically, this study answered the following question/s:

1. What are the lived experiences of caregiving parents of children with autism who search for intervention programs for their child?
2. How do caregiving parents of children with autism make sense of their experience as they continue to search for intervention programs for their child?

3. What are the challenges encountered by caregiving parents while searching for an intervention program for their child?
4. What motivates caregiving parents in searching for intervention programs for their child?

Literature Review

Children With Autism

The autism term which originated from "autos", which means "self" was a Greek word, and was formerly utilized in the year 1908 by Eugen Bleuler who is a Swiss Physician to describe a schizophrenic patient "who had withdrawn into his own world". He employed the word to associate to an individual who exhibits "morbid admiration" and "self-withdrawal" (Pérez et al., 2015). Later on, empirical researches showed that Autism is a disorder under neurodevelopment which can be distinguished by persistent difficulty in communicating and interacting socially across multiple context, restricted or repetitive behavior, interest or at least 2 manifestation of the criteria below (a) stereotypical which is a repetitive motor movement (b) rigid routines (c) strong pre-occupation with unusual object, and (d) sensory issues either hypo or hyper sensitivity to a certain stimuli (Diagnostic Statistical Manual, DSM5). In another related studies facilitated by the National Collaborating Centre for Women's and Children's Health (NCC-WCH) in 2011, the following characteristic are noticeable in children with autism in preschool age which includes language delay or presence of language but in a repetitive manner, unresponsive with others with absence or lack of eye contact and facial expression, preference for solitary play, and the presence of stereotypical and rigid movements.

Percentage of children diagnosed with autism remains high, based from the findings of Center for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring (ADDM) in the year 2016. It was reported that across the multiple areas in the United States there are identified 8-year-old children with autism with 1:68 ratio or 1.5%. It was also shown the higher prevalence rate of boys being identified with autism as compared to girls which is 4.5 times. Moreover, Hispanic children were less likely to be identified with ASD as compared to Black, and White which is the most predominant. In the Philippines, according to Dr. Borromeo of Autism Speak Foundation the estimated prevalence of autism since 2018 until present increased from half a million to a million; although those figures should be cautiously interpreted as some areas in the Philippines was not covered (The Philippine Star, 2014). This growing incidence of children living with autism shows a greater need for available services and support now and through their growing years.

Early detection of autism's symptomatology in a child is essential in order to address it correctly while some researches state that behavioral signs can begin to emerge as early as six to 12 months (Piven et al., 2017). Conversely, according to American Academy of Pediatrics (as cited in Guthrie et al., 2013) most specialists recommend to make a diagnosis when the child reached at least 18-24 months of age because the symptoms of autism may persist to emerge or fade at an earlier age and as the child gets older the symptoms tend to be more stable. However, it should be noted that it is not possible to detect all children with ASD around this age (Stenberg et al., 2014). Furthermore, children with autism vary their signs and symptoms with one another and even some appear to be present in a developing neurotypical individual. This makes it harder for parents and professionals to be certain of its diagnosis.

Behavioral Interventions, Therapy, and Treatment for Children with Autisms

Although researchers identified several behavioral interventions for children with autism, it is still a challenge for parents and professionals to identify the appropriate approach for a single child, because the signs and symptoms of children with autism vary with each other. Moreover, the amount of empirical evidence available regarding the effectiveness of behavioral intervention programs is limited which makes it harder for parents in their constant search of the best approach for their children (Weston et al., 2016). Similarly, due to several limitations in standard assessment which include lack of sensitivity of the tool to measure small or slow progress, extraneous variables that may affect child's performance. Moreover, with the limited information provided for treatment planning, measuring the outcome of an intervention program is also a challenge to professional and clinicians (Bacon et al., 2014).

Only 10% of Filipinos are diagnosed with Autism and 5% are receiving the appropriate intervention program which as of 2017 costs an average of P180, 000 annually, according to The Autism Society of the Philippines. Considering the unique cases of each child with autism, several interventions are also available for their needs, some of the most widely used and with evidence-based results include: ABA Therapy, Early Start Denver Model (ESDM), Floortime Model and Pivotal Treatment.

The widely used and most common intervention for children with autism is the Applied Behavior Analysis or ABA Therapy. It is derived from Behavioral Analysis that focuses on the study of behavior. This therapy applies the approach in molding, eliminating or adding a behavior through reinforcement or punishments from Behavioral Analysis. (a) In order to increase on-task behaviour or social interactions, reinforcement procedure is being utilized. (b) In teaching new functional, social and communication skills, systematic instruction and reinforcement are used (c) Self-control and self-monitoring procedures are being taught in order to establish behaviour which may generalize job-relates social skills; (d) it teaches generalization and transference of a certain behaviour through assignment completion in an exclusive class room to an inclusive and bigger classroom setup; (e) It modifies the study environment when interfering behavior occurs, and (f) it minimizes the occurrence of self-harm or injury and stereotypical behaviours. Moreover, this therapy relies on strict procedure of evaluating the observable behavior objectively and systematically using measurable approach (Center for Autism and Related Disorder, n.d.). Many decades of research have validated the effectiveness of behavioral interventions including the efficacy in “improving language, cognitive abilities, adaptive behavior, and social skills, and reducing anxiety and aggression” (Dawson, 2011). A reduction in autism severity was achieved while intelligence quotients and communication domains indicate a significant level of improvement (Landa & Kalb, 2012).

Geraldine Dawson, Ph.D and Sally Rogers, PhD established the Early version of Denver Model which focuses on 1 to 4 years old children with autism. It is initially based on an application to older children with autism which is called the Denver Model. The Early Start Denver Model (ESDM) targets the social interaction, integrated skills set, and forming personal relationships, these are the usually areas where children are having difficulties. The important elements of Early Start Denver Model (ESDM) include (a) Deeper Interaction between Parent and child (b) Therapy in a form of play (c) Positive and Emotion-based delivery of teaching (d) Centered on positive emotion and harmonious relationship (e) Spontaneous strategies based on ABA (f) Sharing is being encourages in this collaborative session, and (g) Setting aside the goals for neurotypical child while respecting the child’s own pace.

This ESDM is a stepping stone for a child with autism for his/her succeeding education like the Denver Model. It aids the early onset of behaviors which centers on relationship. This, in effect will guide larger social interaction of the child in the future. As such, this model aids child that are having difficulties forming connections within the family or relating to other people. (Applied Behavioral Analysis Program Guide, n.d.).

Floortime intervention is an approach that can be utilized by parents or professionals to maximize the developmental growth of the child. This is an approach that encourages children to young adults to communicate and responds by independent thinking or to find ways to solve the task rather than provide immediate answer to questions This is contrary to the usual education whereby adults show the child the answer to a problem which in effect, make a child become reliant on the process and will have difficulties solving problem on his own. Floortime is an approach for parents and professionals with the child having the authority and taking the lead in the learning process. The three main principles are (a) Parent or therapist allows the child to harness its own motivation by helping the child feel in control, and joining the child’s world by following his/her pace. (b) The co-facilitator aid’s the child in emotional regulation such as solving social problems and processing stress and frustration this would challenge the child to move forward in the developmental ladder; and (c) Thinking outside the box through abstract thinking, seeing pattern, and boosting creativity (The Floortime Center, n.d.).

The Pivotal Response Treatment (PRT) is an approach that uses play to focus on the crucial developmental areas of the child. These was developed by Dr. Robert and Lynn Koegel in the year 1970 at the University of California-Santa Barbara (UCSB). The four main pivotal areas targeted in PRT are as follows: (a) motivation to increase the desire of the child to learn and perform skills associated with good consequences; (b) initiation, by encouraging a child to socialized through asking a child question or getting the attention of the child; (c) Teaching a child to self-evaluate and discriminate their behaviours to achieve independence; and, (d) PRT trains a child to be responsive to numerous cues rather than focus on a single stimuli. The pivotal response treatment wa highly effective treatment as supported by a published research in Behavior Modification journal especially for preschool to middle school students with ASD (Applied Behavioral Analysis Program Guide, n.d.).

Other therapy such as Occupational Therapy are being utilized to help children become independent in performing daily tasks such as taking a bath, eating, brushing and relating to people. Research shows that occupational therapy is an important and effective treatment for children with autism especially when facilitated by qualified occupational therapist. It greatly improves the functioning of children with ASD (Stronelli, 2016). While Speech Therapy aids in children with ASD to engage and improve their communication skills. Reinforcing the social skills equip the children with ASD the necessary skill to relate with others through engaging in a conversation as well as problem solving skills (Center for Disease Control and Prevention, 2019). Evidence shows the significance and improvement of communication of children with ASD through of speech therapy (Lincoln et al., 2021).

Some dietary approaches were also developed to treat ASD symptoms, these includes removing certain food in a child’s diet (e.g glutein or casein) and adding vitamins and minerals. Dietary treatment is being utilized due to the belief that the cause of autism is certain allergen in food or mineral and vitamin deficiency. While there is no medical cure to treat ASD, medications can help ASD individuals function better by alleviating its behavioral symptoms such as excessive level of energy, difficulties to focus, and excessive worrying (Center for Disease Control and Prevention, 2019).

Parental Involvement In An Autism Intervention Programs

Several researches have looked into the role of parental participation as a beneficial tool for early intervention in children with special needs as shown in the research of Mutasa et al. (2013) whereby more than providing financial assistance to the child, active participation such as assisting in accomplishing homeworks, participating during parent-teachers conference and follow up consultations to teachers deem to be necessary. Similarly, early interventions together with family involvement and sensitivity promote best outcome especially in terms of a number of child’s developmental domains (Crowell et al., 2018). Moreover, empirical studies of McConachie and Diggie (2006 as cited in Bennett, 2012) assert the positive outcomes produced by parental involvement with proper early intervention training yielding positive outcomes for children with ASD such as social communication skills. Thus, parental involvement may be utilized as a baseline or guide to emphasize its importance, because it has theoretical framework, background research and conceptual models which serve as its essential foundation (Tekin, 2014).

Lived Experiences of Parents of Children With Autism

Parent’s goes through a process of pre-diagnosis until moving forward to tackle their child’s future (DePape, 2019). Parent’s reaction to the condition of their child varies as other parents are more knowledgeable and open than others. Emotional readiness was seen in some mothers who are open to possibility that their child has autism, while some are resisting due to lack of understanding of the disorder. The slight changes in their child’s behavior were not view as problematic and requiring immediate action. Instead, they dwell on rationalizing the behavior of their child (Gentles et al., 2019). Parents identified experiencing being in denial which act as a barrier in the acceptance process of their child, which also resulted in the late parental engagement to take action. For a period of time, parents try to gather signs in different setting. The information seeking approach varies from each parent, those who are aware of the possibility of autism tries to research specific signs and ask experts to affirm their concern before taking action (Gentles et al., 2019). Seeking professional help and studying further to understand what intervention to use for their child was the most common approach parents underwent upon fully confirming their child’s condition. Moreover, they became more driven in taking action (Gentles et al., 2019).

Parents navigate for available treatment options for their child and see its benefits. However, due to vast information, parents often are confronted in which treatment is effective and if the source is credible. Therefore, parents look for expert’s opinion and look for parents’ review before trying the treatment (Smith, 2020). Parents rely heavily on specialists as they are individuals who will educate, guide and make necessary correction to parents’ therapeutic pursuit. This are group of professionals who specializes in the field (Shenoy, 2017). Parents place importance in communicating to experts especially when they need to determine what best intervention or best practice to choose for their child (Huri, 2018). Furthermore, they rely heavy on evidence-based treatment and back it up with parent’s testimonies. Recommendation from parents in the autism community as well as relatives are very relevant to them. Parents usually went through trial and error in trying to find the suited intervention for their child (Smith, 2020). Parents reported consuming too much time looking for center while doing other things (Laio, 2020). But still, parents exert extra efforts in educating themselves about strategies and interventions that works for others (DePape, 2019). Parents sense of responsibility stretch even more as they dwell deeper with information available about autism, some gather information by reading or joining support groups. Parents are doing all the hustle because they look ahead of the future of their child and think about the long-term outcomes of their perseverance (DePape, 2019). Parents aspire for their child to live independently (DePape, 2019). Moreover, they are worried who will take care of their child or what would happen to their child when they are gone (Topen, 2019).

Autism is a spectrum and each child requires a unique therapeutic approach from one child to another. Moreover, no single therapeutic approach can reverse completely the core symptoms of autism despite the advancement in early diagnosis and intervention (Shenoy, 2017) and therefore, to achieve optimal improvement, and progress of the child, therapy must be continued. Parents then realizes the importance of therapy in child’s progress because the developmental delays must be addressed as well as the other atypical behavior that will unfold over time. Therefore, it is really essential in highlighting the importance of accessing intervention programs and how it must be an on-going process (Karmiloff-Smith et al., 2014) Furthermore, a multidisciplinary approach across the lifespan is required for autism as it is a complex neurodevelopmental condition (Politte, 2015). However, therapy cost is really a challenge, parents need to allocate a budget or find extra income to sustain the therapy session of their child since it’s really pricey (Nltre, 2018). Parents career and finances drastically changes upon knowing their child’s diagnosis. There is a great need to secure finances for the child’s intervention. Parents reported difficulties in finances and tried various means to acquire money, because one income can’t sustain their entire expenses (DePape, 2019).

On the other hand, some parents want to try other therapy because they encountered therapy which doesn’t fit their child’s need. Similar to other researches, parents tried various therapies for their child ranging from 2-12, with speech therapy being the most common, however due to multiple kinds of therapy it is difficult to determine which of these are effective (Altiere & von Kluge, 2009 as cited in DePape, 2015). Parents really need to assess which therapy would fit for their child’s specific concern. Parents also reported having difficulties with finding therapist that would match their preference. The personality of experts is essential to parents (Reddy, 2019). Research shows how encountering poor communications with health care professionals are really happening (DePape, 2019). Moreover, how parents perceive child’s progress are also essential in having a good parent-therapist partnership (Ong, 2019) Parents also indicates their struggles with the distance of therapy center as it acts as inconvenience in terms of transportation (Hutton & Caron, 2015 as cited in DePape, 2019).

Parenting a child with autism is extremely stressful because of the challenging condition present in autism as cited in several studies (Al-Dujaili & Al-Mossawy, 2017; Al Saad & Fido, 2013; Hoefman et al., 2014; Moawad & Zaki , 2016; Rezendes & Scarpa, 2011). Nevertheless, some studies indicate parental resiliency from its negative impact because of hope (Faso et al., 2013) knowing that there is support available within the environment (Ooi et al., 2016). Relatively, positive experiences were the focused of some studies that was generated by children with autism within a family. For instance, parents with children who have autism reported to feel a greater sense of relationship with their spouse (Snyder, 2014), other parent said it boost self-compassion (Neff & Faso, 2014), satisfaction and contentment (Habib et al., 2017) and “redefined the life goals, increased in tolerance, patience, and self-advocacy or assertiveness” especially in giving hope to other parents who have a newly diagnosed child with autism (Mann, 2013). It appears that positive experiences enable parents to better meet the needs of their children with autism, as well as maintain a hopeful disposition for their child’s condition.

Parents also continuously feels motivated to continue their therapeutic journey upon seeing even small improvements in their child's performance (Redley, 2019). Parents' treatment satisfaction drives them to be more actively engaged in their child's care specifically in continuing to find intervention programs for their child (Ong, 2019). Parents also stays hopeful on how they view their child's progress. This positive disposition moderate outcomes by influencing parents' expectation of what they hope to achieve through intervention (Este, 2019). Parents hope for their children varies from simple to the most general of wanting their child to be independent. Parents also emphasized the need to think positively about their situation and just persevere for their child's sake (DePape, 2019).

On the contrary, there are literature indicating a sense of hopelessness in parents who have children with autism. In a study by Weiss et al. (2014), hopelessness is the result of inability to adapt in having a child with autism, but the dedication and persistence amidst having a child with autism also aid parents to function properly and ask social assistance to others. Crisis is indeed subject to an individuals' interpretation of the situation. Parents may believe that they have the ability to be in control of the situation or meet their intended goals (Robert, 2000; Lloyd & Hastings, 2009 as cited in Weiss et al., 2014).

Methodology

Participants

In an interpretative Phenomenological Analysis (IPA) study, there is no specific rule for the required sample size, as IPA is primarily concerned with richness of an individual experience. Moreover, IPA studies benefit more from focusing on small quantity of cases, because of the complexity of most human phenomena. As a rough guide and in practice, between three to six (3-6) respondents can be a reasonable sample size. This will allow researcher for sufficient examination of the convergence and divergence of each case while not being too overwhelmed by the numerous data gathered (Smith et al., 2009).

There were (6) main care giving parents who participated and qualified for this research. The researcher of the study was able to gather the respondents from referrals and those who volunteered upon seeing the call for participant post social media platforms and on autism group pages.

Instrument

This study utilized a semi-structured one on one interview whereby, initials questions were subject to modification depending on the responses of the participants and when important and interesting areas arises while the researcher was asking questions. The initial questions were subjected to validation of 3 (three) subject matter experts (SMEs) in order to help create an effective interview schedule. Then the validated questionnaire was used during the pilot testing with 3 (three) initial participants. Finally, results of the pilot test interview were utilized in order to produce a final questionnaire which was used for the actual samples.

The interview incorporated the following sections:

Interviewee Orientation: This involved double checking if the informed consent was signed and understood by the participant. The researcher also emphasized the important parts of the informed consent, and informed the study participants regarding the purpose or objectives of the study.

Demographic Profile Verification: The researcher double checked the information provided by the participants prior to the interview schedule, and to know where to address the token of gratitude after the interview.

Semi-structured Guide Questions: This was utilized to prompt the study participants in recounting their experiences of seeking intervention programs for their child with autism.

A laptop was utilized since the interview was virtually done via zoom (a virtual platform).

Procedure

Upon receiving the approval from Ethics Review Committee (ERC), the researcher posted a call for participant post online via personal social media platforms. Then the researcher contacted the referrals and those who volunteered to participate in this study. Demographic profile via google form link and Informed Consent was sent to the prospect participants prior to negotiating the date, time and interview platform that we will utilized.

Interview proper started with familiarizing the participant/s about the study's research objectives and highlighting the important parts of the informed consent. This was followed by verifying the demographic profile given prior to the actual interview. Afterwards, inquiry procedure was done where semi-structured questions revolved around the participants' experiences of seeking intervention programs for their child with autism.

Ethical Considerations

This research was subjected for the review and approval from the Ethics Review Committee (ERC) of the University of Santo Tomas-Graduate School (UST-GS). After the manuscript passed the requirement set by ERC, a call for research participant was circulated online. Referrals and volunteers from the online call for participation was given an informed consent form to be signed by the respective participants, and was given their own copy. The researcher also conducted an interview orientation prior to the interview proper to inform the participants about the objectives of the study. The researcher is not part of any autism organization and there would be no conflict of interest with the implementation of this study.

The informed consent explains the important information regarding the research such as the purpose of the study, data gathering procedures, risk and benefits of the participants, and the confidentially measures to ensure the safety and anonymity of the respondents. Recording of the interview session was subjected to the approval of the participant. All sensitive personal information and health data that was acquired were held private and confidential. This study abided with the provisions of the Data Privacy Act of the Philippines.

Codes were utilized instead of actual names of the participants, the voice recording was transferred to a laptop with password encryption, and the recordings was deleted after the transcription process. The interview lasted for 45 minutes to an hour which varies from one participant to another depending on the richness of experience, the participant was able to share. Moreover, the respondents were the one to determine if he/she would like to finish the entire interview for one session or would like to set another schedule or have a short break. The results of the study may be presented in a meeting or a conference and even be published in a journal, however, the respondent's identities shall remain private and confidential.

Since the respondents were asked through a method of one-on-one interview, possible risks, discomforts and inconveniences may arise which was taken into consideration. One of which is the discomfort of sitting for 1 hour or so during the interview process, in this case the respondents was oriented at the start regarding the possible length of interview and how the richness of shared experience can also lengthen the time allotted, given these circumstances the participants are also aware that they can schedule another session for the remaining questions or have a short break/s.

Another one is asking personal or sensitive questions as a part of the study, in this case building rapport was really helpful and essential prior to asking personal questions. Moreover, pre and post debriefing was done and was necessary for the participants to be well informed about the research and be ready for the kind of questions that will be asked to them, as well as provide emotional processing and/or support after the interview. In case they would really not be comfortable, they can withdraw from the study as stated in the separate informed consent given to them.

While on the process of answering questions, participants were asked to recall their experiences, and past memories, there is a likelihood that the participants may feel emotional. Therefore, prior to the interview process, the researcher also informed and asked approval that a licensed and experienced clinical psychologist will be available and can join the zoom meeting, in case they need assistance when an emotional situation arises while the session is on-going.

This research has a direct benefit to the respondents such as the satisfaction that their voice and concerns are being heard, the feeling of relief that someone is concerned about their welfare and wellbeing; and a post-study debriefing that would discuss the generated results of the study and its implication and future directions. Furthermore, indirect benefits included a simple token of gratitude for the participant's time which is ordering for them refreshments and snacks via food courier services since the interview was virtually conducted.

Results and Discussion

This section presents the data collected from the research participants; the researcher explored the lived experiences of six (6) parents who have a child with autism and seeks intervention programs for them, how they make sense of this experiences, their challenges, and motivations. The process of Interpretative Phenomenological Analysis (IPA) was applied to analyze the data.

Each question will be answered through a summary table of themes followed by brief explanation of each theme and supported by the participant's actual statement.

Table 1. *Profile of the Respondents*

Respondents	*Parental Role*	*Child's Diagnosis*	*Severity*	*No. of Intervention Program/s Attended*	*Name of Intervention Program/s*	*Prospect Intervention Program*
R01	Father	ASD	Mild	4	Occupational Therapy, Speech Therapy, Special Education, Brain Fitness Training	Fine Motor Skills Development or Speech Therapy
R02	Mother	ASD	Mild	3	Occupational Therapy, Speech Therapy, Special Education	Applied Behavioral Therapy or Son Rise Program
R03	Mother	ASD	Mild	3	Occupational Therapy, Speech Therapy, Toddler Class	Applied Behavioral Therapy
R04	Mother	ASD	Moderate	3	Occupational Therapy, Speech	Social Skills Training

					Therapy, Special Education	
R05	Mother	ASD	Moderate	4	Occupational Therapy, Speech Therapy, Special Education, Applied Behavioral Analysis	Speech Program
R06	Mother	ASD	Mild	3	Occupational Therapy, Speech Therapy, Special Education	Applied Behavioral Therapy

Table 1 shows the profile of the six (6) main care giving parents of children with autism who qualified with the criteria of the study. Majority of care giving parents who participated in this study are mothers (5/6). Their child is clinically diagnosed with Autism Spectrum Disorder (ASD) with mild to moderate severity level. All the participants' child underwent at least 2 therapy programs in the past and/or still doing it at present. Predominantly they tried Occupational and Speech Therapy combined with Special Education and are still trying to find supplementary programs for their child.

Table 2. *Lived Experiences of Caregiving Parents of Children with Autism who Search for Intervention Programs for their Child*

Superordinate Theme	*Subordinate Themes*	*Emergent Theme*	*Selected Illustrative Quotations*
Process of Searching for an Intervention Programs	Pre-seeking Phase	Being In Denial	"Okay, it's not easy…because of the denial stage…that's what hinders you…You know in my mind, wait! Just wait! He still in school age. His behavior is really just like that, just wait! Do not get into therapy yet, let him be a child first. That is how I approach it." (R02)
		Realization	"Because normally with that age, he should be conversational already, but with him…no, he can't still compose sentences that time…" (R04)
		Acceptance	"We know that autism is a lifelong condition and we want to give our child with her condition…the best life she can have…we been thinking what life she would have and getting ready for it."(R03)
	Actual Seeking Phase	Seeking For Referrals	"Well we ask our doctor…he recommended a place for…we also, we ask our friends…they might know something near our place." (R01)
		Background Checking	"We checked the center in their facebook page and was okay for it since we realized that our developmental pedia is affiliated with it. (R06)"
	Securing An Intervention Phase	Signing Up	"I enrolled him first in Special Education class and went to the recommended center of parents to enrol in OT and Speech." (R04)
		Continuity of Therapy Search	"We are researching about ABA as another option…So I am thinking of trying other therapy. (R06)"

Table 2 shows the lived experiences of caregiving parents of children with autism who search for intervention programs for their child. The findings showed a succession of procedure which is encapsulated in the superordinate theme Process of Searching for an Intervention Program and its three phases which are the (1) Pre-Seeking Phase, (2) Actual Seeking Phase and (3) Securing an Intervention Phase as the subordinate themes.

The Pre-Seeking Phase is characterized by the journey the parents experienced prior to searching for an intervention program for their child, and it's serves as the foundation or starting point for the actual seeking process to take place. It begins with Being In Denial then Realization and finally Acceptance.

In this study, it started with "Being In Denial" as parents reaction to what other people notices with the behavior of their child.

"Actually, it didn't sink in that our child is autistic. It's like.the point is…that's according to the doctor… because we don't know...but from the looks of it… he doesn't look like someone with developmental disorder or like Down syndrome that you can directly see that something is wrong...but with our child you can't see, he is just quiet. (R01)"

"When my son got sick last 2017, he got pneumonia. The nurse told me. "Mommy, did you try to have your baby check?" I responded "For what?" and she said "because he is not responding to an eye contact". I quickly responded "that's just who he is! Maybe he is adjusting to the new environment". But I am not really offended since I am in a medical profession too. (R05)"

Parents themselves identified this state as a recognition that being in denial was their initial reaction to their child's condition based on their own observation.

"To be honest, at first I didn't accept that my child has autism. (R04)"

Parents were also aware that being in denial somehow act as barrier in terms of their immediate action or taking the first step of action for their child benefit.

"Okay, it's not easy…because of the denial stage…that's what hinders you. So how did I come up? When my wedding Godmother told me "you know, you better have him check". You know in my mind, wait! Just wait! He still in school age. His behavior is really just like that, just wait! Do not get into therapy yet, let him be a child first. That is how I approach it. (R02)"

Fathers also experiences denial despite their child's early signs of developmental problem.

"But my husband is also in denial, because according to him he also had delayed speech when he was younger. That boys talk later and that is normal. (R05)"

Realization follows after the parents were able to absorb and contemplate what other people notices with their child.

"Well actually when my child is 2 and 1/2…years old…it seems like the pedia mentioned something…that he is still not talking…so it's like the pedia felt something.…maybe…he is something else…special like that…so we went to the doctor…what do you call those? Just to see if there's really autism. (R01)"

" Ummmmh…because when my child was 1 yr and 10 months or 11 months and our pedia, our general pediatritian, she really counted the words and he noticed while doing the vaccination. No response to name, lack of eye contact, and being rowdy! Atleast, we already know…the importance of intervention...you really need to wake up…that's why in our case we only did 5mins of being emotional…and then, get to work already. (R03)"

"Because there are the "tell-tail signs" with all the books I read, the lining up of toys…no eye contact…not responding when you call his name. So because he is the youngest, I can somehow compare him to his older siblings…it just started with the nurse comment… I just started to compare him…that yes, there's something lacking. He's about 3 yrs old at that time. My sister is a doctor and has connections... the available schedule for developmental pedia is on the province, but that is the nearest schedule. It's already for next week, so we really grab the schedule to have our son check. (R05)"

Other parents started to have their realizations regarding their child's condition when their child's behavior persisted and more evident signs were observed.

"However, when I enrolled him in his school, the teacher is not calling me…but why is the behavior written in the diary "can't sit still", "cannot"…. You know, why something like that already? It's still the first week of class then why is it like that? It should be right to call the parents first right? But why like that? So after a week. What push me to have him diagnose…when I was told by my Godmother, I was still in denial stage…but at the time his teacher told me…as I said we fetch him from school. The teacher said, ma'am your child went to the third floor, in our music room. Because he really like the music… for the whole day… for the whole time that we are doing classes, he can't sit still. He doesn't sit still. He keeps on climbing on the shelves. I said to the teacher, maybe that behavior will not persist, but the same scenario happened the next day. That's it! The reason that pushed me, that behavior….Then 1 week of struggle…and then I said, let's just go. Let's have him check…..I scheduled at the hospital, I got developmental pedia, good thing it was fast…because my Godmother …has a relative, and it's her cousin. So because it her cousin…so cousin try to squeeze her into the schedule. Usually it would take 2 months, 3 months…until a year of waiting for a developmental pedia schedule. Upon calling…they said, yes you are the…by Thursday we already have a schedule. That was fast! yes we will go to the hospital…(R02)"

"When he was still young, he wasn't really talking. And doesn't like to socialize…like that, when there are sounds…he finds it noisy and annoying…he was so emotional…he cries, for example the song is emotional. That time, I was also working…and then my aunt is the one taking care of my son…so every time I went home, that is what I observe. He also learned to walk late…the other people at home notices his behavior. Because normally with that age, he should be conversational already, but with him…no, he can't still compose sentences that time… that's why I looked for developmental pedia…just to check. (R04)"

"I noticed when he is 2 and ½ I observed a certain behavior of our child. The teacher said he is still young, that he can just do therapy. When I saw that the behavior is persisting ….I noticed it, since I am a medical transcriber before… those that I transcribe for developmental pedia, the signs and symptoms is similar with my child. So we scheduled for a developmental pedia and there it was confirmed that my child has ASD. (R06)"

Upon confirming the child's condition with a professional. Acceptance emerges as parents feel the need to do something for the benefit of their child's condition.

"I said let's just go ahead with the recommendations…anyway it's like going to school…you know…it's therapy…let's accept the condition and let's ride with it, for our sons future. (R01)"

"But true enough, you can't do anything about it but to accept, and you really have to educate yourself…as a parent you have to educate yourself of what you can do to your child. (R02)"

"We know that autism is a lifelong condition and we want to give our child with her condition…the best life she can have, of course factoring also the limitations…like if she will have a boyfriend or friends in the future…or what work she will have… we been thinking what life she would have and getting ready for it. (R03)"

"I am still happy knowing that we can address his delays…we just need to act upon it…and accept it…rather than listen to them that he will just outgrow his condition. (R06)"

Other parents’ acceptance comes easier as they exposed themselves to the community that shares the same experiences as them.

“At first, I didn't accept that my child has autism, but as times goes by when I got the chance to be with other children like him, talk to other parents with the same situation like me… I was able to accept his condition. (R04)”

“For me, so that my acceptance part will be easier, what I did…I talk about it…I will say that my child got diagnosed with autism at work…like that…I talk about it…When I read something like this…I am open to discuss. I think that is my outlet, I talk about it! I wasn't snob about it. (R05)”

Actual Seeking Phase illustrates how the parents are actively engaging with other people to gain information, researching and even going to the centers in order to find a suitable intervention programs and conducive facility for their child. This process involves Seeking for Referral and Background Checking.

During Seeking for Referrals, parents are maximizing their information resources to get the necessary details they need while looking for intervention programs for their child. Some parents actively seek referrals from their family, friends and family physician to know a recommended center or facility for their child’s therapy session.

“Well we ask our doctor…the doctor…recommended a place for… if you want to look for therapist for your son…you can go to this center…in this place…he gave a recommendation already…we also, we ask our friends…they might know something near our place. (R01)”

“I have a lot to say, when we ask our doctor, we were given a list of therapy centers near us by Doc R. I also ask my aunt, who is helping me also…ahhh she would tell us what is good to attend…. and also the available interventions. (R03)”

“We ask our pedia….We didn't had a hard time looking for therapy center, because our pedia is already affiliated with a center offering Occupational Therapy and Speech Therapy she already refer the center to us.(R06)”

Other parents, goes to community of parents who have the same condition either through physical or virtual platforms.

“Due to constantly searching… since I ask parents at SPED…the other parents also recommended a near center…there child was also enrolled there. So for me it's an advantage since I know them, the parents, and my son will not be afraid because they knew them…they are familiar faces. (R04)”

“I also asks in the parenting groups that I joined online. If there are post, I asked them. I also ask my sister since he has a special child, if what did she do…we tried to compare. (R05)”

Upon receiving referrals, Background Checking was done by the parents. Some parents inquire over phone calls or with their co-parent regarding the center’s information.

“I did scouting per center and asked about their services and their prices over the phone. We found a center where they train children to be skilled…there I met Teacher A. (R02)”

“Because I really ask parents from the SPED class…I also check there child…If I really see that it's okay and if there's an improvement…there, so far there is a lot of recommendations regarding a center. So that's why I tried it. (R04)”

Other parents look into the different online blog reviews or through post in various social media sites.

“Everything is on the internet nowadays, you can just check reviews. (R03)”

“I really did researches while looking for a good center. Of course I did a lot of readings…I subscribe to a lot of email letter. I am following online support group for my child. (R05)”

“We checked the center in their facebook page and was okay for it since we realized that our developmental pedia is affiliated with it. (R06)”

Parents also exert effort to inspect the center facilities where they will possibly enrol their child.

“Finally, we allocate a day with his dad to do scouting and check the centers ourselves, of course the therapy center have different fee aside from the special school. (R02)”

“I really consider checking the facilities, since one time the center is very near the road. For safety reason. We are really finding facilities which is safe and affordable, we saw another facility with small reception area and too many stairs going up the building, so it's really dangerous for the child. (R04)”

Securing an Intervention Phase. This is where parents signed up their child for an intervention program and still finds prospect intervention to supplement or change the therapy of their child.

Signing Up. Parents proceed with their child’s enrolment as a recommendation of their developmental pedia and sense of urgency to take immediate action.

“The developmental pedia recommended to enrol our son in Occupational Therapy and Speech Therapy while doing Special Education. We also enrolled in brain-enrichment programs and tutorials for his school (R01)”

“I enrolled my child in Montessori School then upon the recommendations we had occupational therapy, speech therapy and enrolled him to Special Education School. (R02)”

“We enrolled her first in OT as a recommendation to start with it first and then after a month we did speech therapy. We also enrolled her to a pre-school toddler class, but on top of that she still have another toddler class. We didn't stop, we really continue...we are very aggressive in doing the intervention. (R03)”

“I enrolled him first in Special Education class and went to the recommended center of parents to enroll in OT and Speech. (R04)”

“I enrolled him first in ABA since I know he really need it for to correct his behavior. Then, occupational therapy…speech therapy alongside with Special Education class. (R05)”

“We enrolled first in Occupational Therapy as a recommendation that it should be the first then Speech Therapy. And we are looking into ABA also. (R06)”

Continuity of Therapy Search. Parents wanted to supplement their child’s therapy for their child to improve his/her skills and achieve his/her great potential.

“We started with a CA center which is near our house. And then we discover another center which is nearer…so we transfer to this center…and then look for another therapy... later on we saw a new center, which is really the nearest in our house…which is walking distance. Aside from regular schooling, we realized that he loves drawing…he loves clay… robotics...so we look for enrichment classes and might do another speech therapy in the future. (R01)”

“I am open to other interventions since there must be a technical part in the development of my child. He is improving, but we still needs more therapy. (R02)”

“We are in the process of looking for a big school…during this pandemic, we been attending seminars like the ABA…keeping abreast with the latest… Interventions for ASD. We are really looking since we know that it's language that she needs to focus, especially the expressive and sort of receptive…she can understand…we are also looking for an intervention…there's one... I forgot…there's still one which is assistive…speech...which was during a seminar. Upon asking if it's fit for my daughter...it's not for productive but to communicate. But there, as long as there's appropriate intervention for her....then...okay...and like what I said...the ABA...Yahhhh....so that's it. (R03)”

While other parents are concern with their child’s behavior and still wants to have a specific form of intervention to manage and resolve their specific concern.

“I am also scared with his socialization, I want to find a therapy for social skill...he just want to be alone…He has also behavior whereby he can't really help himself or being too excited…and I just want to address his mannerism, the screen time and sleeping pattern…because even though his cell phone is already off, he still talks on his sleep, that's what I'm planning to address soon. (R04)”

“Whenever I see a new mannerism or if there still a need…of course with the recommendation of the experts. So, I will look for another intervention that needs to be added. When I saw a new one or when a parent said that they tried this intervention. I will really look for that...will search in the Youtube… will search articles...testimonies...then I will ask the suggestion of the therapists. (R05)”

Another parent is wanting to try another intervention program in the hope that it will be more effective for his child’s condition.

“We are researching about ABA as another option, since I noticed that it's been 2 years already but there is still no progress in terms of his occupational therapy sessions. So I am thinking of trying other therapy. (R06)”

Table 3. *How do Caregiving Parents of Children with Autism Make Sense of their Experience as they Continue to Search for Intervention Programs for their Child*

Superordinate Theme	*Subordinate Themes*	*Selected Illustrative Quotation*
Sense-Making Process of Parents	Therapy as Integral	"It’s not a cure, but it’s helping my daughter’s condition to be managed as she grows…and the earlier you…give it to her…the better the outcomes….And if you stop doing it….you stop hustling it would affect your child…that's why we don't stop doing the therapy and looking for interventions." (R03)
	Therapy as Specialist-Guided	“We really don't have an idea if it is just us. The therapist really helped us what we need to do.” (R06)

Data showed how parents of children with autism make sense of their experiences as they continue to search for intervention program for their child. With Sense-Making Process of Parents as the superordinate theme and (1) Therapy as Integral and (2) Therapy as Specialist Guided as the subordinate themes.

Therapy as Integral. Therapy is important for the child's progress as it helps in the improvement and management of their condition.

"At least, we already know…the importance of intervention...you really need to wake up…that's why in our case we only did 5mins of being emotional…and then, get to work already… Intervention…It's not a cure, but it's helping my daughter's condition to be managed as she grows…and the earlier you…give it to her…the better the outcomes…(R03)"

Autism is a lifelong condition and therefore needs a lifelong tool which is therapy.

"We know from the start that autism is a lifelong condition, and you really have to work hard on it…and if you stop doing it….you stop hustling it would affect your child…that's why we don't stop doing the therapy and looking for interventions. (R03)"

Autism is a spectrum, what works for others may not work for your child, it's really a trial and error and you have to continue doing it because progress varies from one child to another.

"Of course, there's no magic in therapy…you can't just say for 30 day…wow he can completely talk…because autism is a spectrum and therapy process takes time from one child to another….that's why you have to continue doing it…(R05)"

It is an essential tool for a child with ASD to learn certain ways to maximize their potentials be at par with neuro-typical children.

"It means everything, it means everything to the child. Because, a parent would always, would…what… it's not questionable the love of a parent. But it is not just not only love. Did you get it? There should be a certain technique…there should be a certain way, a certain, what? A therapy or intervention that must be done to your child...because if not, he would end up not knowing anything. (R02)"

"Because I want him to be at par with others, to be able to do the things at this age, to see improvements in him. So that when he is still younger he can progress easier, early intervention is important for progress. (R06)"

That's why specialist encourages the parents to continue doing the therapy to really see progress and really address the concerns of children with ASD.

"His pedia told us that we must continue his speech therapy for him to improve more his speech and of course we also saw how he improved during those years of therapy. (R01)"

"There's really an improvement before and after the therapy, what more for a continuous one? If only therapy is free…other parents would be doing it consistently for the benefit of their child. (R04)"

"We can see his potentials and progress as he goes on with therapy…that's why we continuously goes on…since it's the proper and right way to do. (R06)"

And if you stop the therapy, you will see the effect on your child's condition. That's why as much as possible, therapy must be a continuous process.

"My mom just told me that my son is becoming hyper and her description of my son's behavior is a bit alarming. And he ask me regarding the therapy. I know that he is doing well with his self-help and socialization…just a bit more therapy. (R02)"

Therapy as Specialist Guided. Parents viewed experts as essential person in explaining, guiding, and executing the therapy process. They rely on experts such as doctors and therapist as their source guide in their therapeutic pursuits.

"So we just followed the advice of the pedia, because our son has speech delay and lacks focus and attention. So since the doctor said it…so we went to the therapists…and then, according to the therapists…that he lacks focus…he's delayed in speech…so we said …maybe that's it…although physically from the outside...you can never tell...but the therapist…they know better…they know more...so we just listened…so we said…let's go ahead with therapy. (R01)"

"What else, I will stay something…there, of course when the pandemic started, we consider home school totally…but good thing when we went to developmental pedia, Doc R sad no...Don't home school because my daughter may do regular school…so he send also lists of school. Since she will now go to big school. (R03)"

"Doc R is really good...So when we discussed our options…when I asked, if Doc, can I just study something like…behavioral science…or anything that could help my daughter. He said, no, do not...it's great, he said no. Because there are cases…when once it fails...with OT or Speech … the mommy, when it fails…they take it personally…so he said, he really discouraged me with that idea, and we followed his advice. (R03)"

"I want whatever will be good for him, whatever the pedia will recommend. (R04)"

They see therapist as someone who are trained, experienced and has more authority over intervention programs. They are the one who will provide inputs and corrections throughout the therapeutic journey of parents.

"With parents, even though I am educated, I can't stay with him since I'm a working mom. So for me, I still trust, what the therapist knows, which I am not aware and you know, therapist knows better, because they are trained and experienced…so…there's my trust

…so that's why I wanted to see…look for, why am I still searching. Why I still go for it…Because…there is always something new which I don't know, and you therapist you are the one knowledgeable about that, right? So, that's it. (R02)"

"Ummmh, I am open to the idea... trying other intervention programs…. Whatever the therapist will say…because they are the authority…when it comes to intervention programs. (R05)"

"We really don't have an idea if it is just us. The therapist really helped us what we need to do, there would be time that you will really be skeptical if you are doing the right thing or not or you might aggravate the condition of the child, it is better to have a reassurance or corrections from professionals so that we will be confident on what we should do. (R06)"

Table 4. *What are the Challenges Faced by Caregiving Parents as they Seek Intervention Programs for their Child*

Superordinate Theme	*Subordinate Themes*	*Selected Illustrative Quotations*
Parental Struggles in Therapy	Time Management	"I had a hard time with time management…because I am working before I just stopped because of my child…so that I can accompany him to therapy." (R04)
	Therapy Expenses	"Another consideration is the budget, of course therapy is really expensive." (R05)
	Therapist-Client Match	"Before when I was still looking for therapist, I want someone who is kind. I don't care about the skill, I know they are knowledgeable about that, they are skilled…they will not be there if they are not qualified. So I have no say regarding qualification. But I am finding someone with a heart." (R02)
	Therapy Site Proximity	"That's our first consideration, the location, if the transportation is easy since we don't have a car, so we use grab and it's very expensive." (R03)

As per my analysis, several challenges while seeking for and doing the intervention program were encountered by parents. Those Parental Struggles in Therapy (Superordinate Themes) were (1) Time Management, (2) Therapy Expenses, (3) Therapy-Client Match, and (4) Therapy Site Proximity (Subordinate Themes).

Time Management. Parents viewed seeking for an intervention program as time consuming and in the process they struggle to manage their time making "all ends meet" or doing everything that they need to do.

"Time consuming…you really need to look for other options/alternatives. (R03)"

"That's it, our time, when we were really looking for therapy centers… I also did scouting and it took so much time. (R02)"

"At first, I had a hard time with time management…because I am working before…I just stopped because of my child…so that I can accompany him to therapy…so now, I do garage sale outside. (R04)"

"Time, because I worked at night...so the adjustment …my adjustment with time…I have two other kids… of course you can't neglect them even they are okay on their own. (R05)"

Parents are forced to allocate time to accompany their child or check on their child's during therapy.

"Of course the time, the time...need to allocate extra time to be with my son…to accompany him to the therapy program. (R01)"

"So there is really a struggle…with the management of time since I have to check on him. I have a work and my husband too. It's hard because what we got for our therapy schedule is on a weekday and we have work on weekdays. That's why I try to go to the center during lunch time to check on my child. (R06)"

Therapy Expenses. The cost of therapy is another challenge for parents since it is really expensive.

"So…and we feel na…the therapy is of great help…in fact, to the point where I feel…if we can have the daily therapy…just to do the process, right…but it's impossible, because it's very pricey. (R01)"

"I check the prices, I said "Oh Lord!". I check there is 600php/hr that is the usual. There's 1000php/hr. I consulted through phone. There is 800php/hr. They also have a program within a certain year, 100,000php. So I freaked out. It's like, it's not enough for our everyday expenses. (R02)"

"The ABA Therapy is good but have you heard of that center which is so costly. For a single assessment for 2 hrs. I thought it's 3-4 thousands, but it's actually 34 thousand, because they would be flying in their expert…since we don't have here in the Philippines. (R03)"

That's why parents go back to work or find extra means of making money, because therapy would result to substantial amount of expenses.

"Therapy centers, have different prices…others have high prices while other are cheaper. When my child was diagnosed with autism and I saw how it's financially demanding…I really go back to work…I really find a job. (R03)"

“I was able to check various facilities…but mostly have high prices as compared to 1 hour session of other centers. At first we really had a hard time with the finances, since therapy is really expensive…that's why I also put up a business when my child was diagnosed. (R04)”

Truly, one challenges is therapy cost as other parents can’t continue with the therapy sessions of their child due to financial concerns.

“If there is an online therapy that is free, it would be better. But yes, therapy should be paid …But if only the government has a free access to therapy even just online…that is what I observed with other parents, they don't continue the therapy…because of the money concern…so if there would be free therapy, it would really be helpful. If there's a once a week or a month free therapy it would greatly help those who are really in need (R04)”

Parents need to know how to budget their expenses wisely as therapy takes a huge part on it.

“Another consideration is the budget, of course therapy is really expensive. You would really think at the back of your mind while searching for an intervention program…what shall we remove from our expenses? What additional work to do to have extra income? (R05)”

I have 2 other kids who have their own needs as students. Our income should be stable enough to sustain expenses for him. (R05)”

“Of course, financially you really have to separate a budget, we are both working, but it’s very expensive to do therapy and at the same time with special school. (R06)”

Therapist-Client Match. Another parental struggles encountered by parents in the therapy is the kind of therapist and if it matches their preference.

“I am looking for a male therapist at the moment, so there must be a certain authority…to identify himself as a boy. (R02)”

Some parents disregard the qualification as a main consideration since they know everyone in that field is already an expert. And so, they lean more on looking at the personality of the therapist.

“Before when I was still looking for therapist, I want someone who is kind. I don't care about the skill, I know they are knowledgeable about that, they are skilled…they will not be there if they are not qualified. So I have no say regarding qualification. But I am finding someone with a heart, that's the one thing I look after, since when you talk to them. Before, there are therapist which are too stiff, "yes, mommy", "yes, mommy". I saw my son, he will be rolled in the carpet, because he was so naughty. And there is a camera in the room, when I saw in the monitor, I scratch my head in dismay. I said, shall I call a lawyer! Because I don't know the procedure, I said it looks like they are hurting my child. You know as a parent, I can't be like that. So in the long run, I let it be that way...I will trust there...their qualification...what they are doing! (R02)”

And if the therapists are passionate with their job or they are just into the money matter.

“I started reading, that's the reason why when they are not looking…even when you try to pat their back they are not responding. That's when I realized why the teacher can't be so soft hearted in her therapy approach. She has to have authority, because if not, nothing will happen in the therapy session. She will not be followed. But still up until now, when I look into therapist I always check if they are in for the money or they are up to the passion of what they are doing, just two. Because you know, it's just for money, you are just doing it for money but without love, like that. (R02)”

Other parents look into partnership as they work together for the betterment of the child’s condition. They see communication as important and how the therapist delivers it. They also dislike forcing them to buy things they can’t afford and appreciate those therapist that gives alternative or options for them to decide.

“Because what I am looking for is for them to be my partner…there discussion is understandable … those that are not talking down on you when they discuss about your child's just because they are in authority. I want when they talk to me they will use terminologist which are easy to understand and not complex explanation. Those who explains properly…Not forcing you to buy this and that... because they are expensive and giving you options or alternative. And those…therapist…they respond when you text…they respond when you ask something. So far, I wasn't able to come across a therapist that doesn't respond. (R05)”

Some are also fortunate for they experienced the real importance of how the therapist-client match works.

“I only change my therapist once, and I am not the one who made the decision, because it was the project manager ... because the project manager said that "I need to change your therapist, there is lacking, she is not a match for your child". I said okay, it's okay...I really don't know." and she said "no mommy, she was so soft she is not good for your son...because we want your child to learn how to follow and listen because they can be very manipulative"…I thought because he was so kind so it's not just they get paid for it, but because there is a project manager for ABA involved. They really make sure that I have the fit therapist for my child …that's why I didn't change or went to other therapist. (R05)”

There are also lucky parents, who were able to find a perfect therapist which is matched to their child, and tried their best in keeping them. Because they know the tiring process of repeating all the procedure all over again.

"But you know the therapist, they really goes to another center, that's why we try to go after them…although it's relatively far…but still it's manageable… Then even now, our therapist is still the same…they have been with us…up until now. Now, they slowly open…they do home service …good they are available for home service. Another thing…that's why, the constant change of therapist…it causes headaches, as much as possible…we don't like it…because we will go back to zero…on assessment and everything…that's why we made it a point to stick with the same set of experts…so that we will not keep on repeating the process. (R03)"

Therapy Site Proximity. This is one of the important considerations of parents and also one of their main struggles while looking for therapy centers.

"Because my first priority is proximity, since I am working mom. And I have 2 other kids which goes to a school. That is really my main consideration the proximity. (R05)"

Some parents struggle with this because they doesn't have their own means of transportation. And private transportation are very expensive especially on the day-to-day basis.

"That's our first consideration proximity and if the transportation is easy since we don't have a car, so we use grab and it's very expensive. (R03)"

And they know that their child's behavior may be different upon travelling for longer hours and being in a public transportation.

"I am really looking that time for a near center, my son have an issue travelling. He is actually okay with travelling, but we will never know when his behavior will kick in. (R04)"

And so other parents tried their best to change center which are near their house so that they can just walk, save time and money.

"We ask also our friends…if they know a center which is near our house. That's why we also transfer from nearest center so that it's only walking distance, we save time for travelling. (R01)"

Other parents also struggles with therapy site proximity, because they know that long travelling hours and or long distance travel may affect the performance of their child once the therapy session starts.

"I am thinking if we travel far. The child might get stress upon arrival in the center and it's pointless! See, you will travel 1 to 2 hrs...just 1 hr the child is already stress. So I said no… it should be the nearest…the most possible to go to. That is really what I am looking for. (R05)"

Table 5. *What Motivates Caregiving Parents in Searching for Intervention Program for their Child*

Superordinate Theme	*Subordinate Themes*	*Selected Illustrative Quotations*
Contributing Factors to Parent's Motivation	Parental Love	"I think what draw us to really…to look for the therapy is parental love, wanting to see our child have a better future." (R01)
	Parental Responsibilities	"It's our responsibility to provide him with the future that he wants and what will make him succeed." (R06)
	Therapy Progress	"You can really see the difference before he was diagnose and currently…really a major improvement. (R05)"
	Hopeful Outcomes	"We are hopeful that are child will be able to make up with his delays..." (R06)

Table 5 shows what motivates caregiving parents in searching for intervention program for their child. The Contributing Factors to Parents Motivation (Superordinate Theme) are (1) Parental Love, (2) Parental Responsibilities, (3) Therapy Progress and (4) Hopeful Outcomes (Subordinate Theme).

Parental Love: Parents wanting the best for their child.

"I think, what draw us to really…to look for the therapy is parental love, wanting to see our child have a better future. (R01)"

Parents are also concern about what will happen to their child in the future, and how would he live his life?

"Like every time we go back to the doctor…the pedia…my son…is as of now 4 years delay…he is now 8 but he is talking like a 6 years old…we have a concern …since I look forward…a few years from now…like what will happen to him? Right? Since he is our only child…when he reached 20-21…how will he live by? Right? How would he live life? That is our primary concern as parents. (R01)"

Parents are also concern what will happen to their child if they are gone, that's why they tried their best to equip their child with the necessary skills they need for them to live independently.

"That's it, that really an initial thing for parent…what if I'm gone, how about him? Who will take care of him? The way that I take care of him. (R02)"

“Personally, the reason why I wanted him to undergo therapy, so that when he grows up…I can't say, since I have a heart disease. So, he should know how to do things. That he should not need others to change his clothes…to bath him…like that…that he will know what's right from wrong. And be independent. (R04)”

“Our love for him & when I think how can he survive when we are gone...it’s a constant concern (R05).”

“We want him to be independent and give him the best life in the future. Not just now, but when we are no longer around. (R06)”

Parental Responsibilities. Another contributing factor to parental motivation for seeking intervention program is their innate drive to do it, their sense of duty for the benefit of their child.

“So we have to undergo…you know…Occupational Therapy…Speech Therapy… and then upon the recommendation of the doctor, we go for it…I have a far vision for my child that's why we follow the recommendation of our doctor. We want the best for him and it's our duty as a parent to secure his future. (R01)”

“It's our responsibility to provide him with the future that he wants and what will make him succeed. If therapy is what he need and may help him at the moment, we will try to provide him with the best that we can. So that we can provide him with an independent life in the future. Not just today, but to have a wonderful life as he grows older and we are no longer around. We want to give him a life that he deserves and he will be comfortable...where he can improve, there we are willing to try. (R06)”

Other parents do extra mile and try to in line their study to something that would contribute to understanding more their child’s condition.

“That time, I am not yet in my new school, I am still in my old MA school. I don't know anything. That’s the reason why I left Masters in Industrial Psychology to transfer in Masters in Special Education so that I can understand autism more. (R02)”

Parents are also attending seminars and equipping themselves with the appropriate information and resources that would benefit their child’s progress.

“We need to really prepare for it…and luckily my child is still young. So, we still can…she's okay, she's very receptive…to interventions. That's why as you can see… we are very aggressive with interventions for her…and next we attended seminars, that’s how we equipped ourselves to…to know more appropriate intervention for our child. We attend really seminars. We network. (R03)”

“What I am saying is…it's really your own effort and responsibility that’s why it’s good to join to groups…we also have books…yes that’s it…(R03)”

“Of course I did a lot of readings and researches…I subscribe to a lot of email letter. I am following online support group for my child for the benefit of my child. (R05)”

Moreover, parents had a sense of urgency to take action in enrolling their child and networking with other parents which have the same concern in order to help their child progress.

“When my child had a check-up with the developmental pedia and got diagnosed with autism, I enrolled him to therapy and SPED right away and look for other referrals for therapy because it’s my responsibility as a parent. (R04)”

Therapy Progress. Seeing the child’s evident improvement is another contributing factor in parental motivation.

“For a start…when he was in grade 1…for the 1st time he was exposed to many people…the teacher's commented to us he was very quiet and no friends…but when he reached grade 2, he did somehow improved, he has set of friends…that's it and we hope it will continue. (R01)”

“Before he was in the latest center in the school they are just 4 then when he got into kinder they are 13 in the class…then now at grade 1 around 22 students…But now…he can slowly catch up…because he is more exposed to students also…his speech was way better and improving…(R01)”

“We felt na it's actually right. We….we…do not regret…that we put our son into therapies…because we really see…that there is really an improvement.(R01)”

“Now he’s doing chores, I can now ask him to get the clothes from the laundry shop…I already added chores for him, before its 5 now he has 6 chores. Just like boiling the water…there's a lot now…so I said, it's really possible. Especially to parents, he can now do little things. (R02)”

“And then, recently this January, her assessment with Doc R is okay... still mild but she can read… although she’s turning 5…his reading ability is already for 6 years old…she's done with sight reading…then phonics? She reads phonetically I think? There, I think, she can understand it. (R03)”

Parents specifically see the difference before and after the therapy and how it contributed to their child’s progress.

“The therapy really had a huge contribution to my child progress in reading, he was so fast in reading, and he’s so good in reading. He was also an English speaker and I need to teach him Tagalog so that he can socialize more with his peers. (R04)”

“But when I enrolled him in OT and Speech, he can already do things on his own…he can now compose sentences which he can't do before …he plays with other children… he still chooses whom to interact…but at least he is now playing with them. (R04)”

“We really have to consider our child when going out, because of his behavior, and other people who notices may react differently.. But now, he is doing well when eating outside, he follows "oh you sit down". (R05)”

“I am happy seeing him go to the rest room alone…and put down his shorts to pee…now we just want that he totally remove his diaper. But you can really see the difference before he was diagnose and currently…really a major improvement. Now he is showing other alternatives when he is happy like clapping or putting his hand together and looks like giggling, instead of just flapping before. We can also ask him like "get your spoon... where's your glass? You get your glass". (R05)”

“I really saw my son's progress especially in his speech and that's why we want to continue his therapy. (R06)”

Hopeful Outcomes: Parents also stays motivated as they continue seeking for an intervention program because they have positive expectations for their child.

“I am also looking forward to the day when our son will live a normal life, be confident and ready to face the world independently. (R01)”

“So far, we are still positive pa. Would you believe that? yahhh...feeling generally okay, but it could have been better at this point, we think. Yah, yes my cousin, because it’s a spectrum, so we saw…that they are really….really bad cases…which are non-verbal…even here in our neighborhood, we heard them screaming and throwing tantrums. My daughter you can see, she’s manageable… I guess that perspective also helps…to see the glass half full. (R03)”

“That one day he will come out of world or that he will open up and allow us to enter his world… We just let him grow as he grow. (R05)”

They do not lose hope because they are aware of the ways on how to improve their child’s condition, and how other parents were able to do the same. They just have to trust their child and persevere in this journey.

“Also at the same time, feeling hopeful that everything will be okay. We just have to persevere without giving up. (R01)”

“The thing is, there are people with autism, which finishes library science…or information sciences…they do civil service…some nursing…those interventions they had been through…we also try to look into them. Of course…oh there is something like that…you enrolled your child in that school. (R03)”

“I get to understand my child more. I am more at peace knowing that there is a way to improve my child for himself. (R04)”

“We are hopeful that are child will be able to make up with his delays... I can see his curiosity in other things, potentials that other teachers can also see. It's a waste if we will just give up, when we can see that we still can. That there is a result for our hard works, not just us but also our child. All the teardrops, the fear that we went through should not be in vain. That's why, we continuously go on. We are still lucky, that we can provide his needs, not all parents can understand what their child is going through and not all that can understand the situation can afford to provide the appropriate intervention that the child needs, that is the sad reality. That's why, we can't stop because we have the means to provide him with a good life. (R06)”

Conclusions

Parents of children with autism shared their lived experiences as they continuously seek for intervention program for their child. Parents reported how therapeutic process is long and a continuous process with struggles in between. But amidst those challenges, parents remain motivated because they want the best for their child.

This study has shown how parents view their searching process experience and how therapy and specialist are essential tools in their therapeutic quest. Parents realizes how important therapy as part of the treatment process and how it must be continued. They are aware that whatever decisions and outlook they would hold would greatly affect their child’s progress or improvement. Finally, health care professionals in this field must improve their knowledge, skills and be updated with necessary information about autism, because parents are highly dependent on them as their partners in their therapeutic journey.

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