

## **Life stories of caregivers looking after a child with autism in Vietnam**

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**Abstract** - This study aimed to explore how autistic children form lives of people who were raising them through life stories shared by caregivers. The research participants included 11 Vietnamese caregivers who were taking care of children diagnosed with autism. A preliminary interview prior to the study was conducted to determine caregivers who would participate in the research and in-depth interviews were carried out with volunteer caregivers. To determine aspects of life stories that shape caregivers' lives, the study implemented "Life Story Interview" list. Grounded theory and constant comparative method, effective research strategies were used to collect and analyze the data. Interviews were conducted in Vietnamese language. As a result, 6 broad categories of themes were identified related to caregivers' life stories: (1) psychological consultation, (2) emotions, (3) worries, (4) duties, (5) essential virtues, and (6) hopes. Analyses exposed that although caregivers whose children were autistic underwent a wide range of challenges in their daily lives and had concerns for future of children, they did big shot to reorganize their family lives, required themselves highly and never stopped hoping for better life.

**Keywords:** grounded theory, constant comparative method, life story, caregivers, autism

## 1. Introduction

American Psychiatric Association, 2013 identified autism as “Autism Spectrum Disorders” (ASD), a severe neurodevelopmental disorder that starts very early in life. The delay and deviance in social interaction and relationships, in communication and language, as well as in restricted interests and repetitive behaviors are the main impairments (Faja & Dawson, 2006). Research has revealed that it is harder for families to cope with the ASD diagnosis result than that of other disabilities (Neely-Barnes et al., 2011).

To some extent, the autistic child shapes his family’s viewpoint of life and beliefs for the future (Nealy et al., 2012). Families with autistic children usually have a variety of challenges such as unexpected stress, constant health problems, necessary consultation about intervention and education from many psychological experts, difficult disclosure about disorder status of children, and anxieties about their kids’ future. Because of so much energy, finance, and time required during helping children, many families experience crisis (Neely-Barnes et al., 2011).

During the time of intervention, parents tend to rearrange their lives by accepting their kids’ problems, sharing responsibilities between family members, and adapting the social relationship in the new circumstance. (Kogan et al., 2008; Smith et al., 2010). However, the ways families cope with their difficulties might be affected by their cultural background. Thus, when scheduling the coping plans, it is fundamental to consider the culture of the families (Skinner & Weisner, 2007).

In Vietnam, understanding of ASD is limited. Official statistics on this condition has not been obtained, and the prevalence of ASD has not been largely explored in this nation (CLAN, 2010). Referral for ASD screening in Vietnam was prevented from the lack of knowledge about both developmental disorders and ASD by health professionals. Some children were often brought to specific pediatricians; but, these pediatricians did not recognize the level of the child’s problem, or although being aware of the concerns, they could not make any assessment (Vu, 2014).

Furthermore, a very small number of studies of this condition in Vietnam have been conducted and published. Especially, there is no study offering a ‘thick description’ of the lives of children with ASD and their families (Vu, 2014). Besides, only some private schools and centers supplying ASD care for two-to-sixteen-year-old children in Vietnam, and these facilities are also expensive (Pham, 2010). This is one of the reasons leading to the paramount importance of caregivers in the role of helpers for children with autism throughout their lives.

To obtain the study purpose in examining how autistic children create their caregivers’ lives thanks to life stories, many themes were identified. Consequently, these themes play an important role, as a reference source, in assisting other caregivers with autistic children to reorganize their lives to adapt to their living context. This study applied in-depth interviews to explore many life’s aspects of caregivers with autistic children such as their emotions, challenges, and changes in their lives to accompany their children.

## 2. Method

### 2.1 Research design

This study applied the grounded theory developed by Glaser & Strauss (1967), one of the qualitative designs frequently used in the human and social sciences (Denzin & Lincoln, 2005). When applying this theory, researchers collect, refine, and categorize the data (Strauss & Corbin, 2008). They also use the strategies of making constant comparisons and applying theoretical sampling (Creswell, 2007; Locke, 1996; Taylor & Bogdan, 1998). Besides, the constant comparative method is used to develop concepts obtained from the data through coding and analyzing at the same time (Taylor & Bogdan, 1998). Using this method gives the researcher the benefit of beginning with raw data, and through constant comparisons, a substantive theory will emerge (Glaser & Strauss, 1967).

### 2.2 Participants

Participants in this study were a group consisting of 5 fathers, 4 mothers, 1 aunt, and 1 grandmother whose children had been diagnosed with autism. Their background information was shown in Table 1. Purposive sampling was used to recruit equal numbers of male and female caregivers. To select caregivers, I conducted a pre-interview in which information about the study was shared with caregivers who usually told me many matters concerned about ASD when I would like to know as much as possible about this topic because my boy was autistic. Interviews in-depth came after that with 11 caregivers who were willing to be at the pre-interview. All the interviews would be kept confidential and the names of participants were coded. Participants were each given 50 thousand Vietnam dong as a token of appreciation.

Table 1 Descriptive statistics for personal information

Information	Items	N	%
Age of caregivers	20-30	1	9.09
	31-40	6	54.54
	41-50	3	27.27
	51-60	1	9.09
Education level	Master	2	18.18
	Bachelor	7	63.63
	Intermediate	1	9.09
	Secondary school	1	9.09
Occupation	Bank teller	3	27.27
	Housewife	1	9.09
	Lecturer	2	18.18
	Teacher	4	36.36
Age of children	Worker	1	9.09
	5	4	36.36
	8	3	27.27
Gender of children	14	4	36.36
	Boy	5	45.45
	Girl	6	54.54

### 2.3 Data Collection

Before entering the study, the participants were supplied with a participant information sheet and an informed consent form. They were informed that their participation was voluntary and that they might stop participating whenever they wanted without penalty. Each recorded interview was given a particular number, participants were each assigned a code number, all data obtained were only identified by that code number, and pseudonyms have been applied for participants and proper names to ensure the confidentiality of participants.

To explore deeply life stories with numerous sides concerned about helping ASD children of caregivers, the “Life Story Interview” list developed by McAdams (1995) was applied. Nine sections mentioned in the Life Story Interview list are 1. Life chapters, 2. Critical events, 3. Life challenge, 4. Influences on the life story, 5. Stories and the life story, 6. Alternative future, 7. Personal ideology, 8. Life theme, and 9. Other.

However, only four sections were utilized in this study including critical events, life challenges, alternative future, and personal ideology. While the critical events section asked for incidents leading to changes in caregivers’ lives as well as memorable moments making them cheerful and distressed, the life challenge section brought a clear look at their most difficult obstacle and their solution to manage. Besides, in the alternative future section, caregivers were asked about their thinking on their own and their children’s future, and their key trust to guide their lives were expressed in the section of personal ideology.

Only when receiving participants’ permission and volunteering, did I start to use a voice recorder to record the interview which lasted approximately 60 minutes for each? The techniques commonly identified in grounded theory for collecting data are document collecting, participant observing and interviewing (Glesne & Peshkin, 1992). However, in this study, I only invested time in collecting caregivers’ stories and their thoughts from interviews, which were conducted at places selected by participants (usually at their houses). Questions were created to elicit their stories concerned about their ADS children. Although each interview was a little bit different, they all followed the same basic structure whose sample questions are shown below. The interview questions were pilot-tested and refined before implementation. Interviews were digitally recorded, transcribed, and translated into English for coding. In addition, there were so many answers given after open-ended questions were asked that they were grouped into themes to be analyzed easily.

#### Interview questions (Vietnamese)

##### Part 1: Thông tin cá nhân

- (1). Anh/Chị bao nhiêu tuổi?
- (2). Trình độ học vấn cao nhất của anh/chị là gì?
- (3). Anh/Chị làm nghề gì?
- (4). Bé mang hội chứng tự kỷ của anh/chị bao nhiêu tuổi?
- (5). Bé là con trai hay con gái?

##### Part 2: Thông tin về câu chuyện cuộc sống

- (6). Con anh/chị được chẩn đoán tự kỷ bao lâu rồi?
- (7). Con anh/chị có những phản ứng gì khi được đưa đến phòng khám?
- (8). Anh/Chị có gặp trở ngại nào khi đưa con đến phòng khám không? Nếu có, những trở ngại đó là gì và anh/chị đã làm gì để vượt qua những trở ngại này?

(9). Anh/Chị cảm thấy như thế nào về kết quả khám? Xin vui lòng giải thích rõ.

(10). Anh/Chị suy nghĩ gì và làm gì sau khi nhận được kết quả từ chuyên gia? Xin vui lòng mô tả chi tiết.

(11). Những thách thức anh/chị từng gặp phải trong quá trình can thiệp cho bé là gì?

(12). Anh/Chị đã làm gì để tự mình giải quyết những vấn đề này?

(13). Khoản khắc nào anh/chị xem là khó quên trong thời gian giúp con mình?

(14). Anh/chị đã cho bé những gì để đáp ứng các yêu cầu của việc can thiệp?

(15). Anh/Chị đã làm những gì để bé được hưởng lợi? Tại sao anh/chị nghĩ rằng bản thân cần hoàn thành những nhiệm vụ đó? Anh/Chị thực hiện các nhiệm vụ đó bằng cách nào?

(16). Hãy chia sẻ cho tôi cách thức anh/chị đã thực hiện để cân bằng giữa công việc và can thiệp.

(17). Anh/Chị nghĩ gì về các mối quan hệ xã hội?

(18). Theo anh/chị, trong quá trình can thiệp, bản thân cần có những đức tính nào? Những đức tính này đã được thể hiện trong những tình huống cụ thể nào của anh/chị?

(19). Xin vui lòng chia sẻ cụ thể những lo lắng của anh/chị về tương lai của bé.

(20). Anh/Chị có những ước mơ gì liên quan đến cuộc sống của bé?

#### Interview questions (English)

##### Part 1: Demographics

(1). How old are you?

(2). What is your highest education level?

(3). What is your occupation?

(4). How old is your autistic child?

(5). Is your child boy or girl?

##### Part 2: Life stories

(6). How long has your child been diagnosed with ASD?

(7). What were your child's reactions when being brought to the clinic?

(8). Did you encounter any obstacles when bringing your child to the consultation room? If yes, what were they and what did you do to overcome these obstacles?

(9). How did you feel about the consultation result? Please give me clear explanation.

(10). What did you think and do after receiving the diagnosis from the clinician? Tell me as detailed as possible.

(11). What challenges have you ever faced during the intervention for your child?

(12). What did you do to solve these problems on your own?

(13). What was your memorable moment during the time of helping your child?

(14). What did you give to your child to meet the requirements of the ASD intervention?

(15). What things have you been doing to benefit your child? Why do you think that you should fulfill those duties? How have you done to carry out them?

(16). I wonder if you can share me your own way to balance between your work and ASD interaction.

(17). What do you think about social relationships?

(18). What virtues do you need to meet during the intervention process? In which your specific situations were these virtues shown?

(19). Would you mind telling me in detail your worries about the child's future?

(20). What are your dreams related to your autistic child?

## 2.4 Data Analysis

The text was examined, using grounded theory, and the textual data was managed through QSR N6 qualitative analysis software (Richards, 2002). I reviewed all transcripts and allowed themes which were key ideas to emerge from the data. Codes were applied to lines of text related to these themes so that similar ideas could be compared across cases (Boeije, 20020). The process continued until a set of themes was identified and no new ideas emerged. Applying constant comparative methodology, I compared incidents applicable to each category, integrated categories, and their properties, delimited, and wrote the theory (Glaser & Strauss, 1967).

To ensure validity, an expert review was carried out with the assistance of 2 expert reviewers, and to support reliability, the obtained explanations and suggestions were also put into comparison with raw data (Corbin & Strauss, 1990).

## 3. Results and Discussion

As an analysis result, six themes were dictated namely psychological consultation, emotions, worries, duties, essential virtues, and hopes which are illustrated in Figure 1. Following are these themes and sub-themes with a direct quotation of what caregivers said so that transmissibility could be fully supplied (Baker et al., 1992).

### Theme 1: Psychological consultation

Stories concerned about psychological consultation which were shared specifically during the in-depth interviews were really remarkable and thought-provoking. In fact, the interaction with psychologists in ASD diagnosis may leave an important influence on how the families face with the child's disability. The family may suffer disheartening difficulty when getting the initial ASD diagnosis. Parents experience the utmost strain during the diagnostic process (Howlin & Moore, 1997).

What caregivers shared in this theme were making a medical appointment (n=7), taking the child to the consultation room (n=9), and waiting for the examination turn (n=5) which were cited below.

“It took us a lot of time to be able to book an appointment with clinicians”

“Actually I still remember and feel scared of the first day I took my child to the clinic”

“Waiting for being examined, he did not obey me and my wife. We took turns following the baby, sweat-soaked with all three of us.”

### Theme 2: Emotions

Under the theme of emotions, there appeared three sub-themes, namely feelings at the consultation room including shock, uncertainty, and distress, a sense of disadvantage for the child, and calm feelings consisting of sentiments of true love and high responsibility.

The caregivers stated that whether they were the parents of the child or just the aunt or grandmother, with their true love to the child, they felt their child was truly disadvantaged and pitiful. Their two emotion streams dividing into immediate feelings in the clinic and emotions after being really calm to accept the baby's disorder were clearly different.

By analyzing the statements, “shock” (n=7), “uncertainty” (n=4), and “distress” (n=11) were reached out under the sub-theme of “feelings at the consultation room”, which was expressed in the following sentences.

“We were really shocked when the clinician said that we had to pay attention to my child with autism”

“Maybe, there was something wrong with this examination result”

“The clinician said that the syndrome would follow my child for her lifetime and she could not go to school. This made me so hurt”

A sense of disadvantage for the child (n=10) was conveyed as follows:

“It was so sad to admit that my child was not able to do many common things that other normal kids could do easily like running around and laughing consciously”

In another sub-theme, “calm feelings”, the caregivers expressed their sentiment of true love (n=10) and high responsibility (n=9) as following:

“No matter how bad my child's disorder was, he was my lovely angel”

“She needed help little by little from the time she woke up until her bedtime and this was a difficult, not an easy task. If it was true, we thought, nobody, after all, could help her except for us with our blood love”

### Theme 3: Worries

By considering the storylines obtained through interviews with caregivers, the “worries” theme was also reached. They confided that even though trying to be optimistic to fight with the child, they could not avoid certain worries. In their own opinion, they might face a difficult situation when their child was seriously ill (n= 5). They were worried that their child would not cooperate with them and doctors during the disease treatment. Besides, what they couldn't help but thinking was unavoidable old age as well as the death that would come to them (n=10). A question that bothered them was what the child would be like without their caring hand.

Two of their confidences were quoted below:

The child's other diseases

“It is hard for him and me when he was seriously ill”

The old age and passing of caregivers

“Who will take care of her when I am old or not well enough to take care of her while naturally, she becomes stronger day by day”

### Theme 4: Duties

By analyzing the narratives, the theme of “duties” was reached. Under this theme, the sub-themes of “reorganizing family life”, “balancing between job and ASD intervention”, “maintaining necessary social relationships”, “widening knowledge on ASD”, and “earning” were emphasized.

With reorganizing family life, the caregivers stated that rearranging family life was one of the first tasks needed to be put into consideration before actually starting to intervene for the children. This sub-theme was highlighted by fathers (n=5). With balancing between job and ASD intervention, they emphasized that it was necessary to make an appropriate distribution of time and effort so that they could both keep their job and help their children (n=4). With maintaining the necessary social relationships theme, the caregivers thought that to some extent, some social relationships still made them stronger and more confident in supporting their children while others needed to be restricted (n=4). With widening knowledge on ASD, they were willing to learn and discuss all aspects of autism (n=11). What underlined by “earning” was that they did not place great emphasis on making money like they used to do in the previous years (n=9). When being investigated respectively, these sub-themes were mentioned in the following quotes.

Reorganizing family life

“We need to rearrange the family life in the best interests of the child.”

Balancing between job and ASD intervention

“Without a job, we would have no money but we had to make equal between work and intervention.”

Maintaining necessary social relationships

“We still need essential social relationships for the benefits of both us and our child”.

Widening knowledge on ASD

“Many of my child’s behaviors need my effort and time to be understood.”

Earning

“Making money is no longer our top priority.”

Theme 5: Essential virtues

By considering the narrative lines of caregivers during in-depth interviews, “sacrifice” (n=4), “courage” (n=6), and “patience” (n=7) were sub-themes being found out under the main theme of “essential virtues”. The caregivers’ sacrifice was clarified when they said that they pushed their personal activities, habits, preferences, and ambitions to the past if these things did not benefit their children. They also highlighted in “courage” and “patience” sub-themes that they called on all their bravery and persistence to be the bravest and patient warriors in the fight against autism.

The following are some statements presented for these sub-themes.

Sacrifice

“Spend time interacting with my child instead of on my own pastime.”

Courage

“We do not have any choice but to have to be brave to face difficulties.”

Patience

“To achieve a very small goal, we need much patience.”



### Theme 6: Hopes

The “hopes” theme consisted of 3 sub-themes, namely “good health” (n=10), “child’s decrease in abnormal behaviors” (n=11), and “community understanding” (n=7). All caregivers wished everything would be good for their children, for them, and for their lives when they shared their positive ideas about the next chain of days. Not only did they expect to be healthy enough to accompany their children, but they also hoped their children’s behaviors would become more and more conscious and they would be able to attend the school like the other children. Furthermore, they desired to receive acceptance and sharing with their child’s status from society.

These sub-themes were presented in some following caregivers’ statements.

#### Good health

“I wish not to be in serious illness so that I can help my child”

#### Child’s decrease in abnormal behaviors

“My desire is Lam will become an agreeable son, like the other normal boys”

#### Community understanding

“My neighbors will be sympathized with the loud cry and shout at the midnight of my child”

To gain more insight into the life of caregivers whose children are autistic, it is truly significant to scrutinize their life stories. In an effort to achieve that goal, the study has been successful in accumulating and analyzing such heartfelt and touching stories filled with love.

As a result of interviews, one of the most repeatedly shared themes was “psychological consultation” in which caregivers mentioned complications they encountered on the journey for their child to be examined, from booking medical visit, taking the child to another city to see the clinician, to the time being outside the consultation room for the examination turn.

It was clear that parents of autistic children were extremely sad, confused, disappointed, tired, and anxious when looking for a diagnosis for their children (Gray, 2001; Marcus et al., 2005; Altieri and von Kluge, 2009). When making reservations for an appointment, caregivers were informed that the clinicians’ working schedule was full of because too many children need to be psychologically examined and their parents had already booked. They had to wait from days to days whilst they could not understand what was happening to their children whose behaviors were so different from those of other children living around them. Besides, they did not know what to do to help their kids in this period of time and most of them fell into stress. In fact, in Vietnam, until 2000, did the diagnostic label of ASD receive recognition and there was a dramatic increase in the number of children who have been diagnosed. (Vu, 2017; CLAN 2010). ). In 2003, one of the two largest pediatric hospitals in Ho Chi Minh City, the Children’s Hospital 1, reported the first two cases of ASD, but only six years later, in 2009 the number increased up to more than 800 cases (CLAN 2010; Pham, 2010). The National Hospital of Paediatrics located in Hanoi also admitted diagnosing and treating around 6,000 children yearly (Vu, 2009). Nevertheless, this figure is supposed to be representative of only a small proportion of cases (Brown, 2009; Vu, 2009). Besides, in this country, facilities in public children’s hospitals and universities supplying diagnosis services for children with ASD are not only very

limited but also are mostly in big cities such as Hanoi and Ho Chi Minh City. Consequently, these facilities are often in the condition of being crowded and lacking staff, and it usually takes children with ASD some months to have a place (Brown, 2009; CLAN 2010)

Although it was very difficult to get a place, taking the child from a small province to a large city for the consultation was a harder process. Traveling by coach, while for normally developing children, was probably just a trip, for these caregivers' children, was a real challenge. Their children could not suffer from the noise,

crowded and narrow places like in the coach. The child beat the passengers sitting next to him, screamed out of control, cried loudly, and only wanted to jump off the couch.

“We did not anticipate such miserable situations. We had to ask the driver to stop the coach on the road and then took a taxi to get the rest of the way”.

Some caregivers rented a private car even though the cost of rent was very expensive compared to their family's financial condition and they must prepare lots of suitable food and beverage for their child because of his difficulty in eating and drinking. Supporting the findings of this research, Gray (1994) described how poor eating of autistic children left parents strained. Besides, while waiting outside to be called for the turn, caregivers had to help their child to walk around because he protested violently with being seated by running and jumping, banging his head at any place. Gray (1994) also reported a high level of parents' exhaustion because of the destructive behaviors of children with ASD.

After experiencing unexpected obstacles for their children to be examined, caregivers continued to go through a lot of different emotions when receiving the clinician's conclusion. They were emotions in the clinic when caregivers were not calm enough and those after that when they were able to balance their feelings.

When the clinician said that their baby was at risk of autism, they were upset in extreme pain. At that time they did not know what autism was. They simply had ever thought that their child must be too naughty and disobedient. They did not even think of a syndrome whose name they did not know while that syndrome was manifested in their child's body. Van et al (2011) display in the study that knowledge and awareness about mental illness in Vietnam are generally limited. Not only the community but also experts in this field have little understanding of autism (Brown, 2009).

They also recalled that after the first examination at the first hospital, they did not believe in the clinician's conclusion because his diagnosis way did not satisfy them. Many studies exposed that the lack of sensitivity on part of the professionals is one of the reasons for most families to be dissatisfied with the disclosure of the autism diagnosis. (Brogan & Nussen, 2003; Gasper De Alba & Bodfish, 2011; Smith, Chung, & Vostanis, 1994). To make sure, they brought their child to 2 other clinics with 2 different psychological experts whose various conclusions made caregivers even more confused.

“I asked 3 clinicians with the same question: “What is my child's disease?”. The first clinician said that it was “autism”, the second concluded “autistic features”, and the third provided diagnoses such as “follow up autism”. How I can differentiate such complicated concepts. We also seemed to be down when they said that my

child's behaviors resulted from our poor parenting and they could only be well changed with our suitable parental management.”

Clearly, these points of view did not fit current knowledge of ASD which was considered as a life-long neurodevelopment disorder in international mainstream medicine (Vu, 2014). It was unavoidable to face the uncertainties during the diagnosis.

What experts said in this process and their inadequate guidance led the family to an ambiguity (Haldane & Crowth, 2010).

Moreover, in Vietnam, educational institutes that supply formal training with degrees in occupational therapy cannot be found, developmental assessments are mainly conducted by psychologists and education specialists, and the number of physiotherapists in the field of ASD is limited. Although very few key health providers have been trained about ASD, some of them still provide an affirmative diagnosis (Vu, 2014).

The reaction that caregivers experienced in the second stage were that they partly understood their children's misfortunes. ASD is described as a developmental disability with impairments through three areas, namely social interaction, communication, and stereotypic behaviors (Volkmar & Pauls, 2003; Lennox et al., 2005; Frith, 2008). Of course, their children would have trouble in these domains. Hence, they themselves determined, with special love, to find any way in order to help their children who developed differently to overcome difficulties in life. This drove them to unconditional love and the ultimate responsibility to make up for the disadvantages of their children.

Even though reducing stress and identifying the direction in giving the best assistance to their children, caregivers could not help but having a certain amount of anxiety. They highlighted that sometimes they were very pessimistic about the upcoming expectations. The other theme obtained by considering the life stories of caregivers was "worries" in which caregivers expressed their concerns about the time when their children must suffer from other illnesses and when they were older and drew their last breath.

On the one hand, caregivers were afraid that when confronting severe sickness, their children would not know how to show where the pain was and how painful they were. In addition, they were anxious about their children's cooperation ability with the doctor in some situations like when he had swollen gums, had to take blood for tests, or add supplement water. They also worried about their children's aptitude in tolerating illnesses, for example in case he was asked not to scratch even though he was very itchy, or he was required to lie still for 3 hours. On the other hand, caregivers mentioned *their age of elderliness and death which might mean their children's loneliness*. Gray (2002) argued that when raising children diagnosed with ASD, families often undergo physical burdens. When children are little kids, parents are still strong enough to cope with aggressive behaviors; but, over time this becomes more and more challenging (Gray, 1994).

Additionally, individuals with ASD are faced with social isolation, comprising rejection, bullying, and teasing (Carpenter, 1992; Bauminger & Kasari, 2000; Humphrey & Lewis, 2008). Few people with ASD are able to live independently, most of them depend upon their parents or others to be supervised and supported (Vu,

2014). Moreover, from the service viewpoint, in Vietnam, occupational therapy is not yet recognized and adults with ASD cannot live on or receive services from any community-based institution (CLAN 2010). So, no matter how calm caregivers were, they could not avoid definite worries. Admitting not to know what would happen unexpectedly with them, they wished to have someone else who could give his hands to the childlike the ways they were doing for him and could help him if there were problems with them.

In spite of some above worries, caregivers were always consistent with the duties they had set by themselves. They thought that their top priority was reorganizing family life rather than designing exercises for their children because when their lives are stable and they were able to manage their lives appropriately, intervention would be definitely much more effective. It was very impressed that even in such Vietnamese culture, where child caring has been regarded as the task of mothers, fathers in this research showed an important role in taking care of his family and seemed to take up the main duty in helping their children. When life was under their control, positive thoughts gradually dominated in their life and they easily began the fight with autism.

Moreover, it was emphasized that there was *an effective assignment of tasks* among caregivers in families to balance work and ASD interaction. Caregivers in this study stated these two choices, either one spouse quitted the job to follow the child full time while the other still worked, or they both kept working but their shifts did not overlap so they could take turns playing with their children. However, who would keep going to work must be taken into consideration and carefully discussed between caregivers. In addition, caregivers underlined not to think about the promotion at the workplace, they tried to work as common employees. They must be flexible at work, for instance, they talked to their managers to minimize business trips away from home or they volunteered to take up work they could do late at night. As a result, they gradually found great fun from the little progress of their children.

With regard to social relationships, the caregivers disclosed that there were people who have given them the motivation and belief in helping their children. They were the ones who gently gave them a book about autism, shared with them information about a seminar or some other knowledge related to autism. These were the people who always created good conditions for the caregivers to help their children play with their kids and they supported the two children wholeheartedly. These were also people whose children were also autistic and they were willing to tell their experiences and knowledge. Besides, the caregivers tended to refuse some invitations to big parties with drinking friends, to go shopping, or to go to the café just for gossiping.

Furthermore, expanding knowledge of ASD was considered one of the most central tasks by most caregivers when helping children. Caregivers said that it was their happiness to get any knowledge about the state of a child. House (1981) mentioned the importance of giving information about support services and disability to parents whose children were disabled. Skirton & Barr (2007), Bilgin & Gözüm (2009) also highlighted the lack of knowledge as a chief stress factor.

The caregivers in this study assumed that they have tried to assess social media sites even if they were old because they recognized the significance of mass

media in supplying essential information related to autism. They connected with parents whose children are autistic, learned anything useful from their intervention experiences. Furthermore, they watched video clips shared to see if it could be applied to their children, listened to talks of psychological experts to expand their ASD knowledge. With clips made by foreigners, they did not need to understand those foreign languages, they just looked at the activities and then made some reasonable changes before applying to their children.

“I am old so I used to think I did not need to use a phone with an internet connection. I just need a phone to make and receive calls. But since taking care of the child, I have realized that smartphones are helpful to me to understand more about autism. There is no charge for making calls to other parents with autistic children to ask for their advice.”

The caregivers in some cases claimed that they could not have any clear explanation of their children’s behaviors. As an illustration, their children cried then laughed unconsciously regardless of day or night, or they woke up and could not sleep anymore at midnight. The caregivers really did not know what happened to their children and how to handle this problem. From time to time, when the child was walking on the street with their parents, he suddenly ran into other people's houses. What they needed and what they were looking for when doing like that. To understand deeply such situations, caregivers must learn more and more about autism.

As a result of devoting all energies to their children, caregivers did not concentrate too much upon earning money but had their own solution to financial problems. They specifically stated that along with making little money in their own ability, they planned to practice money-saving and organize family activities in a simple and economical way. They determined the items that were unnecessary to spend money on or those that only needed a small amount. For instance, when going out, they could walk or catch the bus instead of renting a private car or in daily meals, it was advised to prepare nutritious dishes instead of too many complicated ones. Neely-Barnes and Dia (2008) indicated that families whose children are disabled have a need of determining the significance they give on disability. They regarded disability as the centre of the problem so they accept to design typical family characteristics.

By examining the life stories obtained, the next theme reached was “essential virtues” with three sub-themes such as “sacrifice”, “courage”, and “patience”. With sacrifice, changing habits to create all suitable conditions for the development of the child were assumed by the caregivers. They gave up or redesigned some recreational activities to benefit the children.

“I still keep going fishing at the weekend but now I bring my child with me. I guide him in very small tasks, from sitting still at one place, placing the bait to the fishhook, pulling the fish up and observing when I take out the fish”

Bayat (2007) supposed that the majority of parents admitted that they become different persons who are more caring and less selfish.

With the sub-theme courage, the struggle for life was underlined. On the one hand, they bravely faced their children’s psychological booms and when their children lost their temper, they would find solutions instead of being in sorrow and helplessness. On the other hand, when they ran into inadequate eye stare at them and

their children or insufficient acts to autistic individuals from the community, they would make an explanation, by anyway, if possible, instead of suffering silent cry or pity. It took them a lot of time to overcome this prejudice to become such really courageous people. When their children display socially unsuitable behavior, parents often encounter disapproving gazes and comments. Because of the normal appearance of the children, they are regarded as not good parents for not using suitable discipline for their children. (Gray, 1993a; Altieri & Von Kluge, 2009; Ryan, 2010).

Furthermore, they were courageous enough to do something that they did not dare to do before.

"What would you do if your child started sleeping at 1 A.M. every night if many ways you had tried to apply did not work, why do not you bravely cut gradually his naps, combined with helping your child with activities that attract his focus ability and gentle physical activities in the daytime?"

They were also confident to tell others that their children were autistic. No longer did they hide or ignore to talk about their children's mental state. Thanks to their bravery, certain success steadily appeared during helping their children overcome some difficulties in life.

One of the most key virtues when accompanying the child that all caregivers mentioned was patience. They master that instructing a task to a child developing normally may take a short time, either was counted by days or hours, however, with the same task, to autistic children, it may take months even years. Similar to this study, Altieri and Von Kluge (2009) found that families confessed to being more patient when having an autistic child. It was said that patience is an indispensable quality of caregivers because without being patient, they could not hone their children with any skill.

"It took me almost 2 years to help my child to ride a bicycle, starting from assisting him to put his feet on the pedals of the 4-wheel bike, coordinating between hands on the handlebar and feet on the pedals at the same time."

In the process of solving behaviors for children, if they were impatient, they would give up halfway with negative thoughts or would beat children out of control. They identified that in order to support children eliminate a behavior, they must persist in handling it for a long time. In fact, some fathers took 11 months to aid their children not to chew without food in their mouths, more than 8 months to get rid of their habit of picking leaves and crumpled them into their hands, around 10 months to stop them holding things to beat unconsciously.

Being with their children moderately leads families to adapt and acceptance of this new situation. Thus, they look to the future with rays of hope. In this research, caregivers expect to have a better life which was shown in the "hopes" theme consisting of 3 sub-themes, namely "good health", "child's decrease in abnormal behaviors" and "community understanding".

When raising and educating their children, families may experience physical and psychological exhaustion (Green, 2003b; Altieri & Von Kluge, 2009). Besides, more than anyone else, they understood the paramount importance of their physical strength in supporting their children. Hence, found many ways to protect their health and desired to be strong. Nevertheless, their biggest dream was still their children moved towards normal development as much as possible, being able to more

concentrate, be more alert, and behave more consciously. Moreover, they were in the expectation that society would have a deeper understanding of autism and would not look at autistic individuals differently in social environments or label them their despair. According to Baltaş (2007), this understanding reduces the individuals' anxiety about the problem, makes them more optimistic about the problem, and enhance encouragement for coping with strain.

In short, even though the caregivers had anxieties because they did not know what would come unexpectedly into their lives, they were energetic and calm to seek solutions to the problems of autistic children and their lives in the most scientific ways.

#### 4. Conclusion

In Vietnam, the lives of children with ASD and their families have not broadly been examined. Little is known about ASD and how Vietnamese families with autistic children live within the economic, social, and cultural settings of Vietnam (Vu, 2014).

Meanwhile, this study exploring the life stories of Vietnamese caregivers with autistic children gives the opportunity to learn their problems related to this situation, and their personal experiences in dealing with it. Giving clues to understanding better about these families, the researcher hopes to partake in enhancing the society's understanding of these caregivers' lives when their children were diagnosed with autism so that sharing and sympathy from society would be put in these caregivers' hands. Moreover, health care systems need to be prepared and should be expanded to small cities and provinces to address the needs of children with disorder status. Furthermore, ASD control efforts would be maximized and the lives of ASD children and their caregivers would be improved.

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