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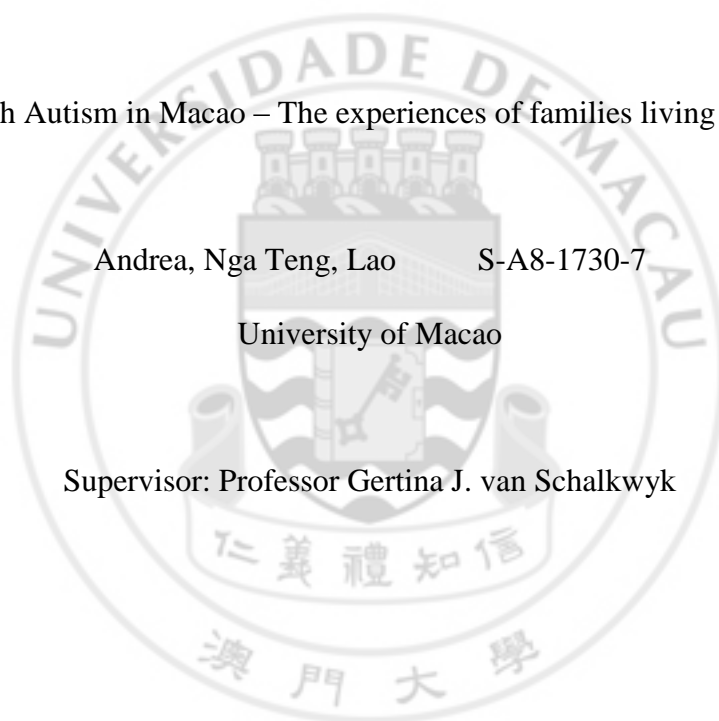


Living with Autism in Macao – The experiences of families living with autism

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Abstract

The purpose of this project was to explore the issues of living and coping with autism in Macao focusing on the experiences and perceptions of families of a child living with autism. The researcher used the Collage Life-story Elicitation Technique (CLET) to collect rich narratives from three mothers and three elder sisters of children living with autism. An interpretive phenomenological analysis was used to examine the data for narrative performances in the non-verbal (collage) and verbal (stories) narratives and to understand the themes related to emotional aspects and social support for the families living with autism. Analysis of the interview contents showed that mothers of the families are particularly stressed, and overwhelmed by strong emotions and denial of the loss of the 'perfect child.' They also experience a lack of paternal support in their families. The siblings in the families are seeking for the attention due to their mother's over-involvement with the child living with autism, and experience a sense of uncertainty and insecurity. Future research may focus on the emotional and stress levels of families living with autism on a larger scale, and explore the influence of culture on family roles and functioning. Societal support should emphasize enhancing the professional and medical system, and encourage involvement of fathers in the caring for their children living with autism.

Despite Macao being a small city-state with only around 570,000 residents, people have very little opportunities to get in touch with children with developmental challenges. Most research focuses on topics related to promoting the economics of this city, and those regarding psychological issues of children and their families have been relatively scarce. Yet it is still very important to acknowledge these issues, especially as the family unit is a central part of many people's lives. Since the dominant culture of Macao is Chinese, taboos often forbid discussions of mental health disorders or developmental disorders in children. However, being isolated from view does not mean that it is unimportant. It is still vital to learn more about children with developmental disorders such as the Autism Spectrum Disorder (ASD) and, together with their families, try to understand how they are coping in this society. Then we can provide appropriate help and resources to encourage the growth and promote the mental health for those living with autism. Hence in this research project I addressed the issue of living and coping with autism in Macao. The project was aimed at exploring the experiences and perceptions of families living with autism in Macao.

Autism, also referred to as autistic disorder, is under the category of autism spectrum disorders (ASD) in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (APA, 2000). Impairments in social interaction and communication, delays in development alongside constricted, repetitious and stereotyped interests, activities and behavioural patterns are criteria for the diagnosis of autism (Gallo, 2010). Co-morbid diagnoses such as lower intellectual ability are common for autism (Bolte & Hallmayer, 2011). Travis and Sigman (1998) also believe that individuals with autism have deficits in attention and with understanding emotional expressions in interpersonal interaction. These can partly explain why

the attention of children with autism differ from those of normal developing children, and why they find it extremely challenging to take part in social interactions.

Data on the children living with autism in Macao is so scarce that it is extremely difficult to find any archives or statistics. Yet, it is widely believed that the number of children who have developmental disorders is increasing, and that professional help is getting more and more insufficient (Leung, 2010). This can be reflected by the fact that there is only one official centre directly sanctioned by the government for helping the children with developmental disorders - the Centre for Psychological and Special Education (CPSE, 2009) under the Education and Youth Affairs Bureau. This centre also provides counselling and assistance for parents coping with other mental disorders. Diagnoses of autism can also be made in the centre, as well as in the two hospitals in Macao, although it is common for parents to take their children to a neighbouring city for diagnosis. Two other government-supported centres - the Macau Child Development Association (MCDA, 2008) and the Macau Association for the Mentally Handicapped (MAMH, 2009) - are also available to provide support for the families coping with mental disorders. The Macau Autism Association was only launched very recently (i.e., in March, 2012 when data collection for this project was already completed) and in the Macao society, children living with autism are still often categorized together with children living with other forms of mental disorders, such as mental retardation. The insignificant amount of data available gives rise to this research, which aims at raising the awareness of Macao citizens, the government and mental health service providers on the existence of children living with autism and how their families are experiencing the phenomenon. With more understanding about real-life case examples it may help families living with this developmental disorder to become more engaged and accepted in society.

Purpose Statement

In this research, the main focus is on the perceptions and experiences of families living with autism in Macao. Two important questions emerged:

- What are the emotional aspects of the family members living with autism?
- How do the family members living with autism perceive the qualities of the social support and society resources?

Through these questions I will gain a greater and in-depth understanding of the families living with autism in Macao. It is also hoped that this project could empower the family and the child living with autism to eventually actually become a part of the society rather than to be isolated.

Method

In this project, I adopted a qualitative approach because it allowed for a more in-depth understanding of the family living with autism; their responses were not restricted to selected choices of answers but they were encouraged to express openly their own feelings and opinions. Moreover, understanding the life stories of the family living in a specific context and exploring the actual experiences they are going through in various aspects in a particular society are also possible with qualitative research (Richmond, 2002). The Collage Life Story Elicitation Technique (CLET) (Van Schalkwyk, 2010) was used to gain a deeper understanding of the perceptions of the families. It is a qualitative and representational technique involving the making of a collage and telling stories for expressing the non-verbal and verbal feelings and perceptions of the participants in a natural context (Van Schalkwyk, 2010). As mentioned by Onwuegbuzie, Leech and Collins (2010), the use of artwork can allow participants to communicate their inner feelings and opinions, which are sometimes hidden below the conscious

level of awareness and more difficult to express in verbal terms. The CLET therefore could assist participants in this research who might have found it difficult to voice out their feelings in words.

It was essential to involve two collaborators, as approved by the supervisor. A participant collaborator, who was working at an institution serving children with autism, was necessary in order to provide access to potential participants for this study. This is because it was difficult to recruit families living with autism due to a lack of systematic organization in Macao. A research collaborator, on the other hand, is familiar with the CLET analyzing process. Her collaboration on interpreting the data was essential to increase credibility and reliability of this project.

Participants

Three Chinese families were invited in early 2012 to participate in the study. Two of the families were recruited via recommendations by a collaborator at a local institution serving children with autism and who helped with distributing information letters to potential participants. The two families who were interested in the project provided their contact information to the collaborator, who in turn informed me. One family was invited by one of the participants who had already agreed to take part in the study.

The use of convenient and snowball sampling is common in recruiting minorities of the society and it can also reflect social relationship of the target group (Noy, 2008). Since each family unit and member is unique and that the experiences of each individual should be valued, a larger sample was not required for this project. Instead it was more important to appreciate and read deeply into each family unit to avoid a vague understanding of the people living with autism in Macao (Onwuegbuzie & Leech 2007).

Each of the family included a mother, a father, an elder daughter and a younger son who was diagnosed with autism. In this project, the three mothers and three elder sisters were invited

as the participants from the families. The mothers were all under forty years old and the elder sisters were all in primary school. Only one mother reported a full-time job but all three claimed to be the major caregivers of their families. From the observation of their living conditions, the three families appeared to have a great variance of income level, lying from rather low to relatively high.

Ethical Issues

All the families received information about the purpose, procedures and related ethical issues such as confidentiality and anonymity before any interviews could take place. I clarified that the participation was voluntary and that they could withdraw from the study anytime they wanted. They were also invited to contact me or my supervisor should they have any questions or opinions upon this study. All data (i.e., interview transcripts, collage, biographic detail, audio recordings) would be kept confidential and would only be used for the purpose of this research. The researcher and her supervisor, together with the research collaborator who aided the researcher throughout the research process, would be the sole persons to have access to the information collected. Others would not be able to have direct contact with the information without the permission of the researcher or her supervisor. All related data of this research would be kept in a safe place in the Department of Psychology of the University of Macau and will be destroyed five years after the publication of this study.

Collecting the Stories

The CLET interviews were carried out at the homes of the participants as requested by the mothers. This was compromised because the mothers all reported to have a tight schedule and that it was inconvenient for them to take their children out for interviews. All the participants took part in the interviews independently; a quiet and relatively private space was maintained in

order to minimize interferences from other family members. Each interview lasted from 25 minutes to 75 minutes: the mothers tended to have a longer interview time than the siblings.

With the consent of the mothers, audio recording was done in every interview for later transcription and translation. It was necessary for the interviews to be done in Cantonese with the families because more precise expressions of feelings and opinions could be obtained through their own language. The communication in native language between the participant and I also allowed metaphors or phrases which could only be understood in the Macao Cantonese context; and that misunderstandings, if occur, could be more readily observed through the use of a language that both parties were fluent in (Winchatz, 2006). English translation was necessary as this study is done for an English research paper. Notes and records were also made after each interview session so that I could reflect on the details during the interview, which could possibly be missed out or forgotten over a period of time (Watt, 2007).

The CLET process involves the collage making and interviewing of the participants and there are five basic steps (Van Schalkwyk, 2010). The first step required the participant to create a collage about her family living with autism with pictures provided. The pictures were cut out from magazines and organized in seven categories:

- a) Individual, which included pictures of a single person of different age and gender;
- b) Group, including group photos of people in different generations;
- c) Scenery, which included photos of different landscapes;
- d) Property, which included houses with interior and exterior;
- e) Artifacts, which included pictures of objects in our daily living;
- f) Animals, which were pictures of different animals and;
- g) Cartoons, which were pictures of cartoons expressing different emotional content.

After completion of the collage, the participant was invited to share the reasons and stories for choosing each picture. It was an important process as the participant conveyed both direct and indirect expressions of her experiences through the content and the tone of her descriptions. The third step required the participant to position herself onto the collage with a reason. Positioning of the self reflected how the participant saw herself in her family and in the relationships with other people while being part of a family living with autism. She was also asked if there were any other pictures that she would like to include onto the collage but failed to do so. This aspect of the interview revealed the absence of important issues that could not be discussed due to non-disclosure, suppressed emotions and/or other significant aspects that might be missing in her life. The fourth part of the interview required the participant to choose similar and different pictures and to discuss the differences. Through this process I could see what might be the contradictory or conflicting issues in the participant's life. Lastly, she would have the opportunity to express how she felt about the collage-making and the interview itself. The session allowed the participant to give her opinions on this project, and provided reflections for both of us on our meeting.

Bias and prejudices. Being raised in a Chinese culture, I am aware of possible bias and prejudice that may jeopardize the outcomes of the study. These concerns should be mentioned to keep the research transparent and hence more credible (Meyrick, 2006). Although stereotypes towards the children may not be a conscious thought, I had to continuously reflect upon my thought processes and how culture might influence my perceptions on children with mental disorders. Also, as a citizen of Macao, I already have had some assumptions and ideas about how the services are provided to people with special needs in the society. These beliefs are mainly negative and I had to recognize my distrust towards the support provided by the Macao

government. I was careful when conducting the interviews so as not to mislead the participants and kept reminding myself about possible biases when analyzing the data. In order to minimize the influences of possible bias, field notes were kept throughout the research process as well. It did not only benefit the understanding of the participants, but it also helped me to always identify my personal feelings and thoughts towards the topic (Watt, 2007).

Exploration on Information Achieved

In this study, an interpretative phenomenological analysis approach (IPA) and a thematic analysis approach was used. IPA allows data to be systematically interpreted in contexts so as to allow the qualitative interpretation to be more credible (Brocki & Wearden, 2006). On the other hand, Braun and Clarke (2006) suggested that unforeseen information may be identified by adopting a thematic analysis; it is also useful in comparing different data sets as required in this research.

I translated the audio recordings for each interview in a first-person perspective within two weeks after the interviews. Although some Chinese words might be difficult, if not impossible, to translate into English verbatim, these meanings were captured by using phrases or longer sentences to explain. Adapted from Van Schalkwyk's (2010) study, three main parts were essential when interpreting the non-verbal and verbal narratives of each participant. Firstly, the non-verbal narrative, which is the collage, was rated using the CLET coding system. I then determined the appropriate metaphoric connotations of each picture on the collage and basic themes were later identified from these connotations. In the second part, the verbal narratives were rated with the same coding system and were read repeatedly to outline possible basic themes as delivered by the participant. The verbal and non-verbal narratives, together with the recognized basic themes and the scores of the coding system were put together on a story grid in

the last part of the CLET analyzing process for each participant. The story grid allowed for a summarized and concentrated record of each participant's narrative performance. It was important in understanding the participant as a whole as the information complemented each other. By looking at it again, I then generated global themes of the particular participant. This was done so by looking at the confirmations and inconsistencies between the two pieces of data (i.e., the non-verbal (collage) and verbal (stories)). The interpretations were further strengthened by the information provided in steps three to five of the CLET interviewing process (Van Schalkwyk, in press).

After the individual analysis of all six participants, the global themes were compared and contrasted across the families. In this project, I first reviewed the themes of the mothers across the three families, and then the themes of the elder sisters across the families were examined. The aim of this analysis was to identify prominent and repetitive themes that helped answer the central question for this project, namely the experiences and perceptions of families living with autism. It is noted that every step of the CLET analysis, from creating the collage to analyzing the data, was carried out with caution. It was through rigorous checking, crosschecking and insights that the research can be made trustworthy (van Schalkwyk, 2010). Furthermore, I had sought for opinions and comments from both my supervisor and the research collaborator during the interview and analyzing process so as to avoid looking at the data in my own perspective only. As proposed by Onwuegbuzie, Leech, and Collins (2010), the credibility was enhanced when the researcher consulted with the literature and other professionals who are familiar with the topic.

Findings

The themes across the mothers and the themes across the elder sisters were compared and contrasted as two separate groups. This was done so in order to observe if there were any prominent threads that run in the same roles of the three families that the research had interviewed. Analysis findings show that there is a considerable amount of similarities in experiences between the three mothers, as well as the three daughters.

The fathers were not included in the study because of their lack of time. Seeing that the CLET would require certain degree of coordination and mental skills, the young children diagnosed as living with autism were also excluded in this particular project as they were only between three to five years old. They were all diagnosed with ASD in Macao at the age of one to two years old. Moreover, all of the younger brothers of the families go to the same institution for developmental stimulation.

Findings from the Collage Narratives of Three Mothers

From Figure 1, it can be seen that the mothers had placed a lot of pictures on their collages regarding their experiences. Their pictures are often very close or even overlapping with each other. It can be seen that they are very involved with their sons. However, the seemingly enmeshed relationship in the family may be harmful to their psychological well being (Laitila, Aaltonen, Piilinen, & Rasanen, 1996).



Figure 1 Collage
mothers of children

Furthermore, the narratives for three living with ASD mothers used cartoons with both strong emotions and the depiction of the perfect child on their collages. This may be explained that they were all going through the grieving and accepting process of their sons' diagnoses (Perrymore, 2005). They were still sad and angry about the diagnoses, and they still had the hope that their sons would be able to function at normal standards. Lastly, a sense of isolation is shown by how the mothers positioned themselves on the collages. The mothers did not relate themselves to the motherly figures they chose for the collages; in stead, they would place themselves at isolated scenery or scenes of distress. This reflects that they cannot actually feel their relationships with other people except with their sons.

Themes Emerging in Collages and Narratives

	Mother A	Mother B	Mother C
Number of Images	14	12	15

Proximity	3	3	3
Scale of 1 (Distant) to 3 (Close)	2*	2*	2*
Narrative Tone	1.5	1	1
Scale of 1 (Negative) to 2 (Positive)	1.5*	1*	1*
Construction	3	3	3
Scale of 1 (Irrational) to 3 (Rational)	3*	3*	3*
Cohesion	3	2	3
Scale of 1 (Descriptive) to 3 (Irrelevant)	2*	2*	3*

* Score for verbal narratives

Table 1 Coding score for non-verbal and verbal narratives for the three mothers

Table 1 shows the scores regarding both the verbal and non-verbal narratives from the CLET coding system of the mothers. According to the data, the mothers all reported high proximity when they were relating themselves with their sons. However, relationships with other individuals appeared to be defective. The tone of both their narratives were relatively negative as they focused mainly on many challenges and emotions they have to overcome. Moreover, they all provided relevant and descriptive information about the focus of the study. From the analysis, the mothers appeared to share emotions and possible conflicts that are alike. Through the themes that were identified, it appears that they are all experiencing strong emotions, undergoing a stressful life, and enduring the absence of paternal help in the family.

Grieving the loss of the perfect child. During the interviews, the mothers had expressed strong emotions related to their distress of having a child with ASD. These powerful emotions are evident in the narrative tone and the experiences they shared, and are not uncommon for parents who go through a grieving process when they receive the diagnosis of their child having to live with a mental disability. The grieving process resembles the loss of the “perfect child” when confronted with having a child whose development reflects an impairment or deviates from

a normal and healthy child. Perrymore (2005) identified six fluid states in the grieving process for the loss of a perfect child: denial, anxiety, anger, guilt, depression and acceptance. The mothers in this study all presented a range of these emotions with the exception of acceptance. Among all, denial, anxiety and depression are the most prominent expressions.

Denial is a subtle feeling that was not directly expressed by the mothers. They did not deny the diagnosis, yet they questioned its validity and may not believe that their children would not be able to function to the standard of the norm. One of the mothers expressed her distrust in the diagnostic report of the hospital. She thought her son did not perform well in the evaluations because of his will, rather than his ability. However, despite her skepticism on the diagnosis, she still chooses to sign up for treatment plans and special education classes for her son. This contradiction can be seen as her unwillingness to fully accept the fact that her son is living with a disability, though in fact she knows it may be true and something should be done to help him. Another mother talks about how she wishes to help the children with the diagnosis to catch up with the "normal standard" and to get into normal schools. This shows how she disbelieves children living with autism are going to grow and strive in a different way.

Anxiety is a very prominent feature among the mothers. One of the mother talks about her feelings from a picture of misty scenery:

"... At the beginning, when we knew about the diagnosis, it was very blurred... I can't see, I can't see the view of the future. When we first knew it at the beginning, it was like this - we couldn't see anything. The view of the future was very blurry."

It is very common for parents to feel anxious when they found out about the diagnosis (Perrymore, 2005). However for this mother, the anxiety is still present and it is expressed in her later narratives when talking about a group picture she has chosen:

"... I really hope him to live a group life... Because family members, I think, it is not really possible, to ask family members to take him as a burden for life. I hope his life, the rest of his life, to be like this. (She cries)."

The mother is still very anxious about the future of her son and she became very emotional when she was talking about it. It can be observed that the anxiety has existed ever since she had discovered the disability and she had been leading this nervous life for a few years.

Anger can also be observed in their narratives. One of the mothers had included angry cartoons onto her collage when expressing the story on how she learnt about her son's disorder, while another talks about her not understanding of why she was 'chosen' to have such a son. Perrymore (2005) states that the parents would question the 'fairness' of the world and that it is possible for displacement of anger to take place. Guilt, on the other hand, was also seen in the mothers of this project. One of them referred her anger towards others as her own personal problem, while another mentioned her husband being 'disappointed' when they found out their son has autism. These sharing show that they somehow think they are responsible for the disability of the child. Again, it is not unusual for them to feel being accountable for something that is actually out of their control when they are facing the loss of a healthy child (Perrymore, 2005).

Depression is an eminent emotion among the mothers as well; one of mothers even reveals that she had to see a professional for her depressive symptoms. This is how one of the mothers described a picture of scenery:

"... I forced myself to have some colours ... to have some hope. That is forcing myself to feel that there is hope."

Her expression on how she forces herself to be hopeful depicts that she actually does not have much hope on her son. Seeing that the mothers still experience denial, anger, guiltiness and intense anxiety, it can be shown that they still have difficulties in accepting the diagnosis of their sons. According to Baker, Seltzer and Greenberg (2011), the inadaptability in living with the disability may also contribute to depression. Therefore it is not in wonder that all the mothers are still very upset about their sons and world still cry when talking about them even though it has been at least two years after the diagnosis.

Stress. The mothers in this study appeared to be very stressed in their everyday lives. According to Kayfitz, Gragg, and Orr (2010), mothers tend to experience higher rate of stress when there was a child with disability at home. It is also reported that caretakers are to show a higher rate of stress and mental health problems if they experience more time pressure in caring for their children living with disability (Sawyer, Bittman, La Creca, Crettenden, Harchak, & Martin, 2010). One of the mothers in this project chose three pictures of a watch or a clock to show her desperateness about time. She thinks it is critical for her child to learn as much as possible when he is still young to compensate for his disability. Another mother talks about how she does not have her free time anymore when she is referring to a picture of open scenery:

"... This picture ... wow, it seems very free. I really want to jump out into it. But then, I am sorry (She cries). I haven't cried for a long time. I think there isn't really any way, to return to the freedom like that of a single."

This emotional narrative does not only show that this mother does not have her own time anymore, but it also tells about the constraints and tensions she has been feeling related to her caring of her child. Apart from the amount of time being devoted to the child, these tensions may arise from a lack of support as well. One mother described her encounter with her son's diagnosis:

"... I looked for methods for helping autism everywhere. But it seemed I could not find ... which road was correct. I was wandering aimlessly."

In a study done by Barker, Hartley, Seltzer, Floyd, Greenberg and Orsmond (2011), results showed that having a small social support system would contribute to greater stress level of caregivers. This mother does not perceive any help or information that she needs, and the uncertainty puts much strain on her. Moreover, she tends to find her daughter being overreacted all the time:

"... My daughter makes events into very big ones. When she does some small things wrongly, after I tell her off, actually normally it would be fine for her, but she would then deliberately hide away and write an apology letter ... she deliberately makes it into a big thing."

She thinks that her daughter, despite knowing she has so much to take care of in everyday life, still does things that tire her out even more. There was obvious blaming in her descriptions and she seems to believe her daughter is not helping her out at all. A negative appraisal to events, such as this one, also exaggerates the stress experienced by the parent (Fong, 1991). It also tells us that apart from taking care of the younger brother, the mother has to care for the elder sister as well. This is true for all the mothers in this study, and that it puts even more time strain in their personal time.

Loneliness and isolation. Another prominent characteristics of the three mothers are that they all perceive a lack of support of the fathers of the households. One of the mothers expressed directly that she does not involve the father much in her life when she is talking about a glass of wine that represents her husband:

"... I have really considered daddy to be dead. (She laughs). Yes, daddy is like, 'I'm drinking red wine, don't disturb me,' then it is fine."

The insignificance of father as a primary caregiver is often in a family with a child living in disability (Bristol, Gallagher, & Schopler, 1988). Being a father, especially in an Asian culture, means to be the main breadwinner of the family (Tseng & Verklan, 2008). They are expected to provide everyday necessities as a way of showing care to the family. However, he is usually not involved in the day-to-day caretaking of the children, leaving this to the mother along. One of the mothers also confirms this by saying that her husband has to work out of town every year and that he is already working very hard for the family. The implied meaning may be that the father of this family works to earn for the expenses required. Yet, this tradition may lead the mothers to feel overly burdened with the work of child-raising, as children with autism generally require more time and attention from their caregivers. Another reason for the detachment of fathers may be their disappointment of having an imperfect child. One of the mothers talks about how her husband reacts when they found out the diagnosis:

"... At the beginning I knew he was disappointed. Then during this process you have to comfort him. That is, maybe because I ... think about how to solve the problems. Then he was like very escaping. This process it was more arduous for me..."

According to Koh and Tan (2000), it is a notable tradition for Chinese to have a son in the family. Therefore, the presence of a son who is disabled may contribute to some dissatisfaction and unwillingness to be involved for the fathers. It may also bring guilt and shame for the mothers who may feel that they have failed the family with this imperfect son (Koh & Tan, 2000). This in turn may lead them to take up the responsibilities themselves and are reluctant to share the responsibilities with their husbands. The inequality in sharing the duties in caring for

the child living in autism then may arouse marital conflict between the spouse as observed in the families of this study (Bristol, Gallagher, & Schopler, 1988).

Findings from the Collage Narratives of Three Sisters



Figure 2 Collage narratives for three sisters of children living with ASD

From Figure 2, it can be seen that the relationships of the siblings with their family members appear not to be too intimate. Borders and extra drawings may be a sign of their desire to connect closer to the family. Moreover, they did not place themselves near characters in a group but put themselves away from other people. There also appear to be constraints in their expressions with the collages. Although they were asked specifically to make a collage about their families, ambiguous pictures were chosen and the whole family units were depicted as insignificance. It is important to note as well that the younger brothers are often absent or portrayed negatively from these collages.

Themes Emerging in Collages and Narratives

	Sister A	Sister B	Sister C
Number of Images	9	12	11
Proximity	2	2	2
Scale of 1 (Distant) to 3 (Close)	1*	2*	1*
Narrative Tone	1.5	1.5	1.5
Scale of 1 (Negative) to 2 (Positive)	1.5*	1.5*	1.5*
Construction	2	3	2
Scale of 1 (Rational) to 3 (Irrational)	2*	3*	2*
Cohesion	3	3	1
Scale of 1 (Descriptive) to 3 (Irrelevant)	2*	2*	1*

* Score for verbal narratives

Table 2 Coding score for non-verbal and verbal narratives for the three sisters

Table 2 shows the scores of the sisters using the CLET coding system. The proximity with other people appears to be rather distant, especially as expressed in their verbal narratives. Their tones are relatively neutral, but there is often a sense of restriction in their expressions. This can also be shown by the high scores on the cohesion scale - they do not seem to be narrating about the topic of family directly. From the analysis, there are some noticeable themes that emerged. There is a sense of strain among them, and they all seem to be in seeking of something that they are lacking.

Uncertainty. The elder sisters of this study are found to be in a considerable amount of stress as they show uncertainties and restrictions in their descriptions. In their narratives, negations such as "I don't know" were frequent and they would find it difficult to put stories into words. Also, though they were asked to make a collage of their own families, very little (if any) pictures representing their brothers were included. The uneasiness they show is not rare in Asian families living with autism, as mental disability is not something that should be discussed openly

(Sage & Jegatheesan, 2010). The feeling of constraints is even more prominent when they tell about their stories. A girl who expresses her fondness of listening to stories, when asked about the time she likes the activity the most, replied:

"When do I like to listen to stories? The time I like best? I like it the best when I tell and listen to stories before bedtime."

It was learnt earlier in the interview that her parents were not free to read her stories all the time, and so it is possible that this girl needs to restrict her preference of the activity to a certain period of time so as to accommodate the family. This sense of responsibility as being the capable child of the family is common in families living with a mental disability (Smith & Elder, 2010). However, it may lead to the stress the siblings need to endure as they should act as the 'grown-up' and mature child of the family. Moreover, stress may be induced by the little brother living with autism directly as they may perform abnormal behaviours (Smith & Elder, 2010). Although this was not expressed explicitly, one of the sisters talks about a picture of a shirtless boy like this:

"But the grandchild he is very, he is very naughty. He, he runs out without wearing clothes when he is having shower."

Since the girl was asked to create a collage about her family, it can be assumed that her little brother is referred as the grandchild in the picture. She describes his uncontrollable behaviour as "naughty" and this naughtiness certainly occupies a part of her everyday life. Though the behaviours may not be threatening, the siblings may still feel troubled by some disturbing acts of their brothers (Barak-Levy, Goldstein, & Weinstock, 2010).

Searching the unknown. The elder sisters of this study all seem to be in search for something that they cannot find in their lives at this moment. This can be told through their collages and narratives. The youngest of the three girls, instead of placing herself near pictures of

families and friends, positioned herself at the back of the collage presenting a picture of flowers. She would like to show the others how beautiful the flowers are. This may mean that she would like to receive more attention than she has now; and that she does not identify herself with the family members she had chosen at the front of the collage. This also confirms the findings of Barak-Levy, et al. (2010) as siblings of children living with autism may receive less mental or practical resources from their parents, as more time and effort are needed for the disabled child. This in turn may lead to a sense of loneliness, as proposed by Orsmond and Seltzer (2007). It seems to support the collage done by one of the elder sisters in the current study who drew a lot of colours and frames to occupy the spaces between the pictures. It can be interpreted that she would like to connect the interpersonal relationships that may not be adequate in her life right now. The third sibling expresses in words how nearly all of the cartoons she chose would really like to achieve something:

"... This sea turtle really wants to go the, returning into the sea to find her mummy ... "
Then, this dog wants to go and play here ... It (a parrot) really wants to try to learn to fly..."

This is a strong sense of seeking for a right and pleasant place in her narratives. This subtly tells us that she is not satisfied with her life right now and she would like to find the better. Yet, she does not mention about what causes the cartoons to want to leave their original places. Instead she reasons their desires as personal preferences. This may be that she is not consciously aware of the insufficiency in attention or care she is at the moment given, and that she is internalizing her longings to a sense of confinement in the current situation. The internalizing of behaviour towards oneself has been found in siblings living with autism in Taiwan (Gau, Chou, Lee, Wong,

Chou, Chen, Soong, & Wu, 2010). As Taiwan and Macao share a similar cultural background, it may be inferred that the elder sister in this family may be facing the same challenge.

Reflections and Recommendations

Two core issues emerged from this research: the emotional well being of the participants and their experiences with social support and resources. From the stories it is not difficult to see that both the mothers and the sisters of this study experience relatively negative emotions in their lives living with autism. They are under a considerable amount of stress that they seem not to be able to overcome yet. The mothers expressed explicitly their sadness and anger during the interviews; they also shared the stress they feel about caring for the children in the family and the time constraints. Although the sisters did not talk about how they feel directly, it can be inferred from their narratives and collages that there are many constraints in their lives, mostly related to having to live with autism on a daily basis. The negative feelings may be exaggerated by the inadequacy of social support. The mothers seem to be affected by the under-involvement of the family, and they do not appear to have significant help from other relatives or friends. It seems that the mothers find the resources for autism is insufficient in Macao, and the help from professionals is not satisfactory. The sisters can also be seen as lacking the parental attention and support that they require.

Although the experiences of the participants in this study may appear stressful, all the mothers did report a gradual improvement in mood since they learnt of the diagnosis. According to Wakimizu, Fujioka, and Yoneyama (2010), caregivers tend to become better in coping with the challenges they face as time press on. Therefore it can be seen that they are still in the process of accepting their sons as needing special care, though they may not have achieved the state at this moment because their sons are still relatively young at age. Moreover, the cases of

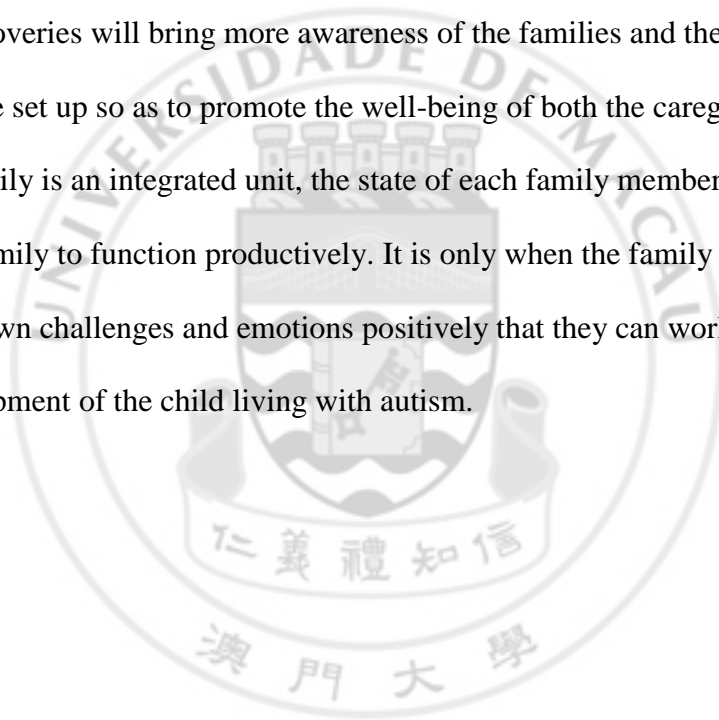
this study only represent some individual experiences in three of the families living with autism in Macao. Future studies may focus on the stress and emotion of families living with autism in Macao on a larger scale, so as to identify the common challenges that the majority faces. Also, influences of culture on the roles in families may be explored to identify stressors for caregivers.

Nevertheless, the interviews have reflected issues that may be affecting other families as well as these three. The inadequate information provided by professionals, for example, is harmful to caregivers. According to Davies and Hall (2005), poor information sharing by professionals may leave the parents feeling isolated, distressed and helpless. Therefore it is vital for the government to acknowledge the improvements needed in the medical system so as to promote the psychological well-being of those who are caring for children living with autism. Therapeutic help such as sharing responsibilities and information with the caregivers, as well as educating them on how to modify the behaviours of their children, is helpful in reducing distress. (Bristol, Gallagher, & Holt, 1993). Moreover, observations on the lack of involvement in paternal help induce some insights to lessen the burden of maternal responsibilities in caring for the child living with autism. The government may help in promoting the direct inclusions of fathers with their children by inviting them to therapy or medical sessions. In an article by Carpenter and Towers (2008), fathers express their desires to be involved in the lives of their children, who are living with disabilities. This may also be true in some families in Macao: some fathers may want to help but could not do so directly because of the cultural expectations of a father being only the breadwinner of the family. The active invitation in the participation of fathers in raising their children with autism may help to alleviate the pressure being put solely on the mothers. As parents play an important part in the quality of the sibling relationships of their children (Sage & Jegatheesan, 2010), they should also be educated on how to cope with the

healthy siblings and recognize their needs. This is essential in benefiting the development of the siblings of children living with autism.

Concluding Notes

This research aimed at understanding the experiences of families living with autism. From the findings it could be seen that the mothers and sisters of the families in this project were under great pressure and constraints that somehow impaired their lives. Also, they are in need of the social support and attention that will ease the distress they are feeling right now. It is hoped that with these discoveries will bring more awareness of the families and their needs, and that help systems will be set up so as to promote the well-being of both the caregivers and the siblings. As the family is an integrated unit, the state of each family member is to be adjusted well to allow the family to function productively. It is only when the family members are capable to cope with their own challenges and emotions positively that they can work together to promote the development of the child living with autism.



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