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Siblings' experiences of growing up with children with autism in Taiwan and the United Kingdom

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Abstract:

Background: A child's diagnosis of autism impacts their whole family, in both positive and negative ways, that may be influenced by cultural beliefs. **Aims:** We aimed to describe the experiences of mothers and typically-developing siblings of children with autism in two cultural contexts. **Methods:** Fourteen mother-sibling dyads from Taiwan and the UK participated in semi-structured interviews. **Results:** Whilst there were similarities in sibling experiences, a negative tone regarding the influence of autism was more evident in Taiwan, where families also cited societal judgement and cultural-specific expectations. In the UK, a more balanced tone was apparent: mothers emphasised educating and involving the siblings. It is speculated that UK siblings had a greater understanding of their parents' stress, leading to more adaptive family dynamics. Various types of support service were mentioned in the UK, whereas the availability of social services and support appeared to be relatively limited in Taiwan. **Implications:** Our data suggest that cultural context may have a significant impact on the responses of the family members. This is mediated by both differences in attitudes and traditions, and availability of resources. Support for family members needs to be sensitive to such cultural differences, as well as recognising positive experiences.

What this paper adds

This paper reveals how parents and siblings of children with autism, in the UK and Taiwan, describe and consider their coping strategies. The data supports a family systems approach, revealing a reciprocal relationship within families, between parent and sibling coping strategies. Open communication is identified as a key factor. Typically developing siblings are aware of the impact that their coping behaviours have on the rest of the family, and can reflect on their efficacy - especially in the UK. They understand why their parents use certain types of coping strategies, and also learn from their parents' modelling to expand their variety of coping strategies. Other factors outside the family also have an influence: for example, parents' perception of the outside world affects the social support their family seeks, especially in Taiwan.

The research has relevance for family support practices. Parents might need encouragement to identify the coping strategies their typically developing children adopt in dealing with situations, as these might sometimes be performed in subtle ways. Parents may already be aware of the impact of their own coping styles on those used by their children, but highlighting the need for awareness may sometimes be useful. In addition, health practitioners need to take relationships within families, and between families, into account when supporting family members to develop an adaptive coping style.

1. Introduction

Autism is diagnosed by persistent deficits in social communication and social interaction across multiple contexts, alongside restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013). It is a life-long condition, contributing to stress within families that results from a variety of factors acting and interacting (Myers, Mackintosh, & Goin-Kochel, 2009). The strain on financial and emotional resources associated with raising a child with autism may result in family conflict which can affect the psycho-social adjustment of every member, including siblings. However, positive family experiences are also very much evident in the research literature (e.g., McHale, Updegraff, & Feinberg, 2016; Petalas, Hastings, Nash, & Duff, 2015). What is less clear is the extent to which culture shapes these family experiences.

As emphasised in theoretical models of sibling development, such as the sibling embedded systems framework (Kovshoff, Cebula, Tsai, & Hastings, 2017), it is essential that we consider the influence of the whole family system, and a range of ecological factors, including the wider culture, on sibling outcome. Factors such as social support, financial resources, societal acceptance and accessibility of services may all be associated with parental stress which in turn may influence sibling adjustment (see also Saxena & Adamsons, 2013).

Furthermore, the experiences of parents and typically developing (TD) siblings (hereafter, just "siblings"), and the strategies they use to adjust to having a child with autism in the family are different (Lovell & Wetherell, 2016; McHale, et al., 2016; Vasilopoulou & Nisbet, 2016). For example, while parents may focus on how to improve their child with autism's abilities, siblings may care more about the behaviour of their brother or sister with autism which makes them feel embarrassed (Lock & Finstein, 2009). It is therefore essential to understand family experiences from both parent and sibling perspectives. Recently, research has begun to examine siblings' experience using self-report (e.g., Hastings & Petalas, 2014; Macks & Reeve, 2007; Rodgers et al., 2016; Smith, Elder, Storch, & Rowe, 2015; Tomeny, Baker, Barry, Eldred, & Rankin, 2016; Tsai, Cebula, & Fletcher-Watson, 2016). In these questionnaire studies, several factors have been found to correlate with sibling adjustment, such as demographic variables, the profile of features in the child with

autism, social support, coping styles and Broader Autism Phenotype traits. However, it remains unclear why some siblings develop and use specific coping strategies and adjust more positively than others.

Despite the social interactive differences associated with autism, positive relationships with non-autistic siblings are evident and are characterized by reduced conflict and competitiveness compared with those of typically developing children (Kaminsky & Dewey, 2001; Knott, Lewis, & Williams, 1995; Rivers & Stoneman, 2003). Additionally, interviews with siblings show that they appreciate the unique achievements of the child with autism, and learn from them (Mascha & Boucher, 2006; Petalas, Hastings, Nash, Dowey, & Reilly, 2009).

This research in Western settings highlights the importance of understanding the family impact of autism, including listening directly to the views of siblings and not just parents. Relatively little research has investigated the experiences of families with children with autism in Eastern countries, though, and even less has contrasted sibling experiences between two different countries (Tsai, et al., 2016). Bachraz and Grace (2009) suggested that when having a child with autism, families reconstruct and draw on cultural beliefs to interpret their experiences. Moreover, when facing challenges, siblings may use culturally-specific coping strategies to deal with stress in order to meet their family's expectations (Tsai, et al., 2016).

In cross-culture studies of families with children with autism, there is some evidence of both similarities and differences in family experience. For example, research examining outcomes for siblings found that UK siblings were more affected in terms of total difficulties and peer problems, but Taiwanese siblings were affected more in prosocial behaviours (Tsai, Cebula, & Fletcher-Watson, 2017). Similarly, Lin, Orsmond, Coster, and Cohn (2011) found that Taiwanese mothers used more problem-focused and emotion-focused coping than did their American counterparts. Differences were also evident in terms of maternal well-being and social support across the two countries.

Research is beginning to unravel cross-cultural similarities and differences in the experiences of families of children with autism utilising maternal and sibling self-report measures. However, there is now a need to explore these using qualitative methods, in order to better understand parent and sibling perspectives, based on their own lived

experiences. Understanding cultural differences in coping and adjustment has a key role to play in practice. Research shows that if age-appropriate information and support are provided, siblings can benefit from better relationships with their autistic sibling (Mandleco & Webb, 2015; Petalas, et al., 2009; Roeyers & Mycke, 1995). However, what is unclear is whether and how this information and support needs to be tailored for children in different cultures. Therefore, a qualitative approach was used in the present research to explore individual and cultural influences on parent and sibling experiences of family life and support in Taiwan and the UK.

2. Methods

2.1 Methodological approach

The interview study was guided by the Interpretative Phenomenological Analysis (IPA) approach, which focuses on people's experiences and perspectives and how individuals understand their world (Smith, Flowers, & Larkin, 2009). As Smith et al. (2009) state, IPA is a suitable approach when the research questions focus on investigating the person-in-context. The IPA approach has previously been used to explore the experiences of parents of children with autism (Cullen-Powell, Barlow, & Cushway, 2005) and of siblings (Petalas, et al., 2009; Petalas, Hastings, Nash, Reilly, & Dowey, 2012).

2.2 Participants

The interview study was a follow-up part of a wider study of sibling adjustment in Taiwan and the UK (N = 155) (Tsai et al., 2016). Invitations to participate in interviews were emailed to families in the wider study with similar demographic backgrounds first, in order to form a relatively homogeneous sample. The response rate was low, and so, the invitation emails were sent out again, this time to all the families who had participated in the wider study. There were 7 dyads of mothers and siblings from each country that participated in the interview. The participants from the two countries were fairly similar in terms of demographic variables, severity of symptoms in the child with autism, parental and TD siblings' Broader Autism Phenotype (BAP) level and their adjustment difficulties (Table 1). The total number of children in the family was 2 – 4 in both countries. The age of children was similar, although with slightly higher upper age in Taiwan. Additionally, there were no girls with autism in the UK families, but two in the Taiwanese. It is also noted that, in

comparison with families who declined participation, the interview families were similar in terms of demographic characteristics, although in the UK families the parental BAP level was somewhat lower and siblings' self-report adjustment difficulties were higher in the interview families, compared to those who declined participation.

2.3 Interview procedure

The focus of the interviews was mainly the experience of siblings, but this was contextualised (mainly through the mothers' interviews) within family life more broadly. Semi-structured interview questions explored sibling relationships, adjustment, coping and social support. Mothers and siblings were asked about similar topics, although the questions were slightly differently, to ensure role and age appropriateness. Further detail on the specific interview questions is available in (Tsai et al., 2016).

Interview questions were first developed in English. The translation of the interview questions into Chinese was done by the first author and then discussed with colleagues with translation qualifications to maintain consistency of the interview questions across the two countries. The interviews were conducted by the first author either during a home visit, online video call, or on the phone according to the mother's preference.

The average interview time was around 30-40 minutes per person. When the interviewer first arrived, both the mother and the sibling were given interview information sheets and sufficient time to discuss any concerns about the interview. After obtaining permission from the mothers and siblings, interviews were conducted individually. Each parent and sibling received a £5 gift voucher (or 250 New Taiwan Dollars) after the interview. The interviews were entirely conducted in the interviewees' first languages, either Chinese or English.

The study followed the Code of Human Research Ethics (The British Psychological Society, 2014), The University of Edinburgh Research ethics and procedures, and it was granted approval by the School of Education ethics committee. It was also made clear that participants could withdraw from the interview at any stage, and we were mindful of any signs that participants were uncomfortable or no longer wished to participate.

2.4 Data analysis

All interviews were professionally transcribed, and the Chinese interviews translated by a professional translation company. A back-translation procedure was also used to check the semantic equivalence of the quotations (for further information on this process see Tsai et al., 2016).

In keeping with the phenomenological aspect of IPA (e.g. Smith, 2017; Smith et al., 2009) the researchers sought to understand the individuals' own perceptions of their experience, without extensive prior theorising. However, this undertaken in IPA through a process of reflective, interpretative activity closely tied to participant accounts of their lived experience. Data were analysed using IPA guidelines (Pietkiewicz & Smith, 2014; Smith & Osborn, 2003). The first author followed a process of repeated reading, annotation, and reflection. The first author then extracted key sections of text, representative of each emerging code from the transcripts. When the emerging codes from the data were consistent, these codes were then clustered together to form subthemes. The co-authors matched the codes with subthemes independently, and cross-checked agreement between them. When there was disagreement, a process of discussion and, where necessary, amendment of the codes and subthemes was undertaken until all the authors were satisfied. The research team then looked at the relationships between each subtheme and clustered them together to form the major themes. The initial groups of subthemes were checked to see whether they could be combined or split up to reduce overlap and redundancy among the subthemes. Any subsequent generalisations about the experiences of siblings of children with autism more broadly are made cautiously, mindful of the idiographic nature of IPA (Smith, 2017).

3. Findings

Four themes appeared in the data for both Taiwan and the UK. These four top-level themes were the same across both countries, indicating that there was commonality in experience across the two settings, although at the level of the sub-theme and specific category, there were marked differences. Even though some of the themes have the same title, at times the interpretation and content differ somewhat between the two

countries. Taiwan and UK findings will be discussed side-by-side, providing contrasts where appropriate, and illustrative quotes as needed.

3.1 Theme 1. The influence of autism

The first theme (see Figure 1) captures how family members had been directly influenced by the child with autism. This theme includes how the child with autism's behaviour influences family interactions with wider society.

A sub-theme which emerged for both countries was the positive influence having a family member with autism had on the whole family, including descriptions of enjoyable activities with the sibling (especially in Taiwan), and explicit recognition of benefits (mostly UK). Most UK siblings gave some examples to illustrate how their siblings with autism influenced them in a positive way, but this was less apparent in the Taiwan data.

> *I actually find it really good that I have a brother……I would be very lonely and if I didn't have him I wouldn't be who I am today. So yes, he has made me who I am today. I find it really well that I have him. (UK-4S)* [1]

Parents and siblings did identify some limitations and concerns, and a feeling of distance between siblings. Both Taiwan and UK siblings had a strong sense of responsibility for looking after their siblings with autism and shared a major concern about how their brother or sister would progress in the future. Some siblings worried whether they would be able to look after their siblings with autism in the future, and that others might bully their autistic sister or brother if they (the TD sibling) could not look after them. The Taiwanese Mothers also mentioned the presence of conflict, and expressed concerns about whether their TD children would be well adjusted in the future. Furthermore, the Taiwanese mothers revealed an implicit worry about the negative impact on sibling characteristics, such as being unable to communicate things clearly and lacking self-confidence. Most of the mothers in Taiwan also felt anxious about how their TD child's married life might be affected by having a sibling with autism, which was never mentioned by the UK mothers.

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[1] All the quotes are anonymous and identified by codes. TW stands for Taiwanese families, while UK was for the UK families. 'P' means that the quotation is from the parents, 'S' refers to the quotation from the TD siblings. The same number stands for the same family members. For example, 'TW-2P' means that this quotation is from the Taiwanese parents whose family is coded as 2, while 'TW-2S' is from the TD sibling in the same family.

It appeared that dealing with opinions of others was quite stressful and embarrassing for the Taiwanese families, especially for the mothers, something which might relate to the mothers' support-seeking behaviour (see Theme 4). Some of the Taiwanese mothers taught the TD siblings not to talk too much to others about their diagnosed siblings and expressed that they would rather keep such matters inside the family. Those mothers also mentioned having children with autism being seen as a stigma, and a lack of empathy from others.

> *Mum told me not to tell other people about this, so I don't really talk about my brother [sibling with autism] with others. (TW-2S)*

In contrast, the UK families appeared more able to look beyond the diagnosis and felt that they were the same as others. A few mothers and siblings in the UK mentioned that they did not define their children with autism by the diagnosis. Even though the different abilities of children with autism might affect their family's ability to do some activities, the UK mothers said they still tried to do things like any other family and enjoyed doing family activities together. Those mothers still required all their children to behave according to certain standards. All these features, however, were less apparent in the Taiwanese interviews.

> *[Child with autism] sometimes gets a bit more slack from me and my husband but I don't really expect the kids to give him anymore slack apart from because he is younger…. I think the major factor in [child with autism] getting more time just now is because he is younger as opposed to because he is autistic. (UK-6P)*

[Insert Figure 1 here]

3.2 Theme 2. Family resilience

The second theme (see Figure 2) focuses on how families respond and adjust to stress. This theme reflects mainly the mothers' process of adjustment in response to having a child with autism, the stress they have been facing and the role of help from others. Mother and sibling coping styles are also discussed in this theme.

Both the UK and Taiwanese mothers mentioned the importance of looking on the bright side, and of giving themselves some private time to take a break. While mothers acknowledged stress and negative impacts in both countries, the UK mothers placed slightly more emphasis on keeping calm, so that they could make the best decisions for their family. Meanwhile, the mothers in Taiwan emphasized how they transformed the

experience to handle the stress and valued their inner strength. Thus, amongst the Taiwanese families this theme is more related to mothers' own personal resilience than to the family as a whole.

For mothers in both countries, raising children with autism was seen as a learning process. It was quite common for mothers to attend training courses as a way of developing coping strategies. Parents discussed quite a number of different coping strategies, whereas siblings discussed a more limited number. For the siblings aged around 9 to 10 years old in Taiwan, feeling anger and upset was frequently mentioned. However, this was not the case for the similar aged siblings in the UK, who instead expressed acceptance and open attitudes towards their siblings with autism and the social life around them.

> *They [sibling with autism] would know how to make their own little short games. I am learning that in IT right now so that is really amazing that they know all about that. (UK-3S)*

Older siblings in both Taiwan and the UK expressed a certain degree of suppression and felt that they had no other choice but to take avoidant coping strategies.

> *I'm more pessimistic. I think of myself really badly. There are some issues that I'd deal with, but others I'd let them rot. (TW-5S)*

Older siblings in both countries explained if there was nothing they could do could make things better, they would prefer to just give in to their siblings with autism to avoid unnecessary conflict. Some older siblings in the UK expressed their worries of adding extra pressure on their parents' shoulders.

> *When I [TD sibling] know there is something that I can't help or really make better, I don't really like to tell them [parents] because I know it will upset them more that they know that I am sad as well. (UK-7S)*

Relatedly, only in the UK did mothers commonly mention how they tried to act as models for their TD children in order to teach them how to deal with the stressful situations, and to let their children know their feelings were acknowledged.

> *Yes, but I don't think it is going to be too bad. I think nothing too worrying will happen… Cross that bridge when it comes to it. (UK-2S)*

> *I think our approach is generally one of being positive and just dealing with situations as and when they arrive …. (UK-2P)*

As illustrated in these quotations, in addition to mentioning the importance of a positive attitude and acceptance of their children's situation, the UK mothers showed a general attitude of not worrying too much about the future, which appeared to encourage siblings to view the future in similarly positive ways.

[Insert Figure 2 here]

3.3 Theme 3. What we do as a family

In the third and the fourth themes, the cross-cultural differences were most evident. The third theme (see Figure 3) related to the relationships within the family, and how parents expected and viewed the siblings' role in the family. It encompasses how the siblings were involved with, and responded to, expectations from their parents. Mothers from both countries expressed how their TD children share the responsibilities of being part of the family, from sharing the housework to looking after their siblings with autism when parents were busy.

The feeling of differential parenting also appeared in both Taiwan and the UK sibling interviews. However, the UK siblings focused more on understanding the difficulties of their siblings with autism. This might be linked to the fact that mothers in the UK reported providing information about autism for their TD children in the early stages post-diagnosis. By using materials like books or DVDs, the mothers tried to educate their TD children and involve them in the family adjustment process. Most siblings in the UK sample expressed a greater degree of understanding regarding the need to give way to their siblings with autism.

> *We got some books that were age appropriate ...... It kind of explained a lot of things that they previously had not understood or thought were not fair or ... why certain things that [sibling with autism] did didn't make sense to them. We sat down together and watched a couple of DVDs that explained autism. And they thought it was really good. And off the back of that I said 'if there is anything that you want to talk about with us, then you are free to talk to us at any time'. (UK-2P)*

In contrast, the Taiwanese mothers expected the siblings to understand the challenging situation well, without much support. Some Taiwanese mothers expected that their children would understand what autism is like simply from their experience of interacting with their siblings. Some siblings could explain certain behaviour characteristics related to autism, but there was a gap between mothers' expectations of

siblings' understanding and their actual level of knowledge. The word 'should' was mentioned by most of the Taiwanese mothers in the interviews:

> *I think he [TD sibling] should have understood better and should not have such a response because he knew what his elder brother [sibling with autism] was like ... I had already devoted so much to take care of my son, but I didn't know why he, being a normal child, couldn't understand. (TW-1P)*

> *...as if it was my [TD sibling] fault ... Mum would say, 'Why don't you yield to her? You know very well that she [sibling with autism] has problems.' (TW-1S)*

Perhaps as a result of this expectation-knowledge gap, the Taiwanese siblings appeared to feel more negatively about differential parenting. In contrast, the UK siblings were better able to explain their siblings with autism's difficulties and (therefore) the reasons why their parents needed to sometimes have different standards for different children. It is speculated that these cross-cultural differences were linked to the greater understanding of autism and explanations provided by mothers in the UK.

[Insert Figure 3 here]

3.4 Theme 4. The support needed

The last theme (see Figure 4) is related to the support that families receive and the types of support they report needing. This includes informal support from friends, extended family members and partners. Formal support includes access to professionals and help from the school system.

Mothers in both countries mentioned that the support they needed varied with different stages and that they had clearer ideas of how to access resources after years of experience. Both the Taiwanese and the UK mothers valued the support of friends they had met through groups who had similar experiences. Such social networks were not limited to information exchange only, but, most importantly, provided emotional support.

In the Taiwanese families, tension between mothers and their extended families was frequently mentioned, even though often their extended family members did not live nearby. The tension was mainly caused by disagreements about childrearing and extended family members' lack of knowledge of autism. Stress in relation to interactions with extended family members had made this potential source of informal support less helpful amongst the Taiwanese families than in the UK families.

I could go home and lock everything outside, and escape from my parents or parents-in-law, who have quite a lot of opinions on how we should bring up our children. I was often criticized. Though I let them to do so, I still persisted in my own way. (TW-7P)

My mother is still living, and my husband's parents, they are all in their 80s now, but they have always given a lot of support through the years. They are not local, so not daily support, but they have always been happy to come and help in the holidays and spend time with the boys. .... We have had good strong family support which I think is very important. (UK-1P)

The role of the partner was also different in the Taiwanese and the UK families. Most of the Taiwanese mothers described that it was themselves who consulted professionals about their children. Due to a lack of time, and having responsibility for the financial resources of the family, fathers were less available - and less capable of taking care of their children with autism than mothers. Thus, in some cases, this seemed to cause lack of mutual understanding and make communication difficult between mothers and fathers. In contrast, in some of the UK families, the mothers reported that both parents would work part-time, or choose a job with flexible working hours.

In the Taiwanese families the lack of understanding of autism alongside negative social stigma had made the parents feel distant from their friends or parents. The parents in Taiwan found it stressful to explain the situation to the people around them, who were 'not in our shoes'. As some Taiwanese parents discussed, the help or concerns from their friends would become an extra burden sometimes.

Sometimes I'd talk to my close friends, but most of the time, I don't think they understand. Sometimes I even feel hurt by their reaction, so I wouldn't go into details anymore, and I will avoid this topic in the future ... I wouldn't go into too much detail about my child. (TW-1P)

Siblings from both countries also expressed their need for support from their friends, as it helped them to release their stress if they had someone to talk to. However, some siblings found that their friends were ignorant about autism, so support from their friends was limited. As the Taiwanese mothers emphasised keeping family things inside the family, the Taiwanese siblings were also influenced by parents' attitudes toward the support they had received from friends.

I think they don't understand what it is like to live with him [sibling with autism]. I don't think they realize what it means. I do think they are ... 'oh she [TD

sibling] has had a bad day' and stuff but I don't think they actually realize what it is like. (UK-7S)

All of the Taiwanese and UK mothers mentioned that they actively sought formal support resources in relation to autism once their children had been diagnosed. They also participated in training programmes or joined support groups to enhance their knowledge of raising a child with special needs. Both groups note that support in rural areas was less available than in urban areas. Some mothers, both in Taiwan and in the UK, found it most challenging in the early stages since they had to fight in order to get support for their children, while others found the process went smoothly.

The UK mothers revealed that, as time went by, the support they needed might be different, and that they could reach for the support whenever it was needed. For example, mothers mentioned that their TD children would go to the support group whenever they needed - some went to the activity occasionally, while others found the service more suitable in their teenage years. Overall, the UK families appeared to be more proactive in utilizing the available support and resources than the Taiwanese families.

[Insert Figure 4 here]

4. Discussion

This qualitative interview study explored TD siblings' experience, and how culture may influence their experience. The interview data from both the Taiwanese and the UK families formed four themes. In each theme, mothers and siblings expressed their own experiences of living with a child with autism in the family. There were some similarities between mothers and siblings, and also between the two countries, most notably concerns regarding the future and the stress siblings perceived from both parents and the society around them. Both parents and siblings in Taiwan and the UK expressed the positive experiences that the child with autism brought to the family, similar to reports in previous studies (e.g., Cridland, Jones, Stoyles, Caputi, & Magee, 2016; Petalas, et al., 2015). However, there were many cross-cultural differences too.

The data suggested that the Taiwanese mothers appeared to have higher expectations of their TD children than did their UK counterparts, corresponding to broader child cross-cultural research (Phinney, Ong, & Madden, 2000) and the impression was also

consistent with our previous questionnaire study (Tsai et al., 2016). For example, compared to the UK parents, the Taiwanese mothers seemed to have higher expectations of how siblings would cope with challenging situations, but without always providing a great deal of information about autism. Phinney and her colleagues (2000) found evidence that Chinese parents have stronger expectations of their children's obligations within the family than do their Western counterparts. Obedience and respect for parental instruction is seen as the performance of filial piety ('孝順') and a key virtue in Chinese culture (Ho, 1996). Previous research has suggested that Chinese caregiving obligations are bonded with its cultural philosophy (Holroyd, 2003). Our data suggest that these caregiving obligations also influenced how the Taiwanese mothers passed information on to their TD children. An emphasis on family responsibility was also shown in the Taiwanese data, whereas in the UK families this responsibility was addressed differently, by trying to involve TD siblings in family activities, but also respecting them as individuals.

In terms of coping, older siblings in both countries expressed the need to give way or to distract themselves (which could be categorized as avoidant coping) in order to handle the situation. This means of coping has been linked with higher levels of adjustment difficulties (Tsai et al., 2016). Whilst it might be a concern in the long term if siblings use this coping strategy, it is possible that an avoidant coping style functions as a protective response to a situation that is not fully understood or that individuals perceived as uncontrollable (Donaldson, Prinstein, Danovsky, & Spirito, 2000). As Ross and Cuskelly (2006) note, some siblings view distraction as a very effective coping strategy when facing difficult situations with their siblings with autism. Several quotes from the UK siblings expressed that if they could not really do anything to make the situation better, they would prefer to keep things inside them or do nothing about it. It also appeared that the UK siblings took this approach, in part, because they did not want to worry their parent, by sharing their difficulties. This may explain the larger difference between parent and self-report sibling adjustment difficulties in the UK than in Taiwan in our previous questionnaire results (Tsai et al., 2016). Our findings are in line with Tritt and Esses' (1988) based on Western culture, suggesting that, although they seemed to have quite open conversation about autism more broadly, the TD siblings were aware of parents' stress and would keep their worries inside rather than let their parents know about the difficulties they had experienced.

The attitudes of the UK siblings seemed, to some degree, to be similar to those of their mothers, with some mothers consciously modelling coping strategies. This supports our previous questionnaire study findings of some links between parent and sibling approaches to coping found in UK but not Taiwanese families (Tsai et al., 2016). Difference in how parents deliver the information regarding autism and their ways of coping might contribute to this. It has been found in Western research that open communication between family members and adapting coping approaches to fit the needs of the family can improve family coherence (Altiere & Von Kluge, 2009; Greeff & Walt, 2010). Previous work has also found that if parents have a positive attitude toward their children with disability, it appears to promote siblings' relationships and understanding (Lobato, 1990). Lobato's research showed siblings' reactions were consistent with parents' modelling, acceptance and attitude toward their children with disabilities. Therefore, the more open communication between the UK parents and the siblings, and the parents conscious modelling of coping approaches might have helped them to develop better mutual understanding and more similar approaches to coping.

Some of the siblings in Taiwan and the UK experienced signs of differential parenting as upsetting and unfair. Such negative feelings have been found to be harmful to siblings' relationships (Rivers & Stoneman, 2008). Chinese parents tend to express their warmth and care in a more subtle and implicit fashion by being sensitive to children's distress and providing instrumental support (Chao & Tseng, 2002). However, there is a risk that TD siblings might be less aware of such subtle and implicit support from their parents and hence feel undervalued, or that their parents have a preference for their siblings with autism. It is speculated that Taiwanese parents tend to deliver information regarding autism more vaguely than the UK parents, and this perhaps explains the lower level of acceptance of differential parenting amongst the Taiwanese siblings. The present interview data also supported the importance of both parents and siblings acquiring knowledge regarding autism, whether this is to help parents develop suitable behavioural expectations of their TD children or to increase understanding of differential parenting in the siblings. However, further research is required to confirm the links between siblings' negative feeling towards differential parenting and the lack of knowledge of autism in the Chinese families.

The Taiwanese families had 'close' relationships with their extended families, but these relationships also appeared to be more tense than those in the UK. Research on Western families has indicated that grandparental involvement could help to share responsibility for child-care, and could provide emotional support to decrease the level of parental stress (Lee & Gardner, 2010). Chinese families tend to have a strong bond with their extended families, and also value the filial piety to the elderly which all family members should respect and obey (Mehta & Ko, 2004). Therefore, input from the older generation can add extra stress to the parents of the child with autism. The tension between extended families might also influence siblings in Taiwan, although this was not clearly apparent in the present study. It is speculated that, although the family relationships in the UK are sometimes characterised as being less close than those in Taiwan, they may be somewhat less hierarchical. This may result in the greater involvement of the partner and the greater sharing of information about autism with the siblings and grandparents, leading to more harmonious relationships. As proposed in the sibling embedded systems framework, parents often endorse the prescribed cultural values and adhere to the social norms when bringing up their children (Kovshoff, et al., 2017). Since the severity of the children with autism in the two countries did not significantly differ in the present study, engrained cultural philosophy may be one of reasons that the patterns of experience were different in the Taiwanese and the UK families.

The difference in perceptions of societal attitudes toward disability and receiving informal support from others were notable between the mothers in Taiwan and those in the UK. Concerns about the perceptions of society and the caring burden in the Chinese families seem to be two core issues in both present and previous literature (Holroyd, 2003; Mak & Kwok, 2010; Tait, Mundia, & Fung, 2014). Perceptions of social stigma were certainly more apparent in the Taiwanese families. It has been suggested that feelings of discrimination and stigma may restrict parents of children with autism from seeking support in Chinese cultural contexts (Mccabe, 2007), and this was also evident in the support-seeking behaviours of the Taiwanese siblings in the present study, some of whom were encouraged to not discuss autism with others. If this experience in common in Taiwan, then the reduction of social stigma would allow for greater use of social support and age-appropriate resources to allow parents to discuss autism and

associated issues like coping strategies with the siblings, which in turn is likely to improve Taiwanese siblings' experience.

Adapting the support according to different cultural contexts is vital (Kim, Sherman, & Taylor, 2008; Taylor et al., 2004). If the findings are representative of the experiences of Taiwanese families more broadly, it would suggest that the social support system in Taiwan, especially formal support, still needs to be further developed to fit its social context. There is no value in offering additional social support if societal factors mean that people will be reluctant to access that support. In Taiwan, a cultural change in the perceptions of people with disability is clearly needed (Chen & Shu, 2012). This could perhaps be done in a similar manner to UK anti-stigma campaigns and research[2,3] aimed to reduce prejudice and discrimination towards disability and mental health conditions. Positive attitudes have increased following such campaigns (Evans-Lacko, Corker, Williams, Henderson, & Thornicroft, 2014).

5. Limitation and suggestions

Inevitably, as with much research in this field, the study did have some limitations. There were slightly different approaches to recruiting participants to the wider study in the two countries (Tsai, 2016). Families who took part in the interview were broadly similar in a number of demographic characteristics to those who chose not to participate. However, with much research in this field, participants in this research were all volunteers which might contribute to a certain degree of bias, with parents who were particularly concerned or less stressed about their TD children's adjustment perhaps being more likely to agree to take part in the study. This possible volunteer bias is difficult to examine or overcome, given the sensitive nature of the family research. Another issue was that despite the fact that the present research did not limit which parents participated, all of the parents in the interview study were mothers. Previous research has found that there are some differences in terms of coping (Hastings et al., 2005; Kaniel & Siman-Tov, 2011; Pisula & Kossakowska, 2010) and in viewing their children's adjustment (Griffith, Hastings, & Petalas, 2014) between mothers and fathers of children with autism. Furthermore, although the translation of interview questions

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[2] http://www.time-to-change.org.uk/

[3] http://www.ucl.ac.uk/pals/research/cehp/stigma-research

was reviewed by qualified translators, a more detailed process which included back translation may have resulted in greater similarity in the nuance of the questions in the two countries (Guillemin, Bombardier, & Beaton, 1993).

Further research could target how siblings appraise their situation and its relation with coping. Other researchers have demonstrated the role of parents' appraisal in terms of coping (Tunali & Power, 2002; Twoy, Connolly, & Novak, 2007), however, less has focused on siblings, particularly in non-Western contexts. Future research should also investigate cross-cultural aspects of sibling adjustment through different stages of their life, especially when they reach adulthood (Gray, 2002; Hastings, 2007; Orsmond & Seltzer, 2007).

Despite its limitations, this study is one of only a few to explore the siblings' experience by interviewing both mothers and children, and in both Chinese and Western culture settings, and thus contributes to the literature on families of individuals with autism. The focus on a select group within IPA limits the extent to which findings from the present study can be generalised. However, this study has demonstrated both the positive and negative impact of having a brother or sister with autism for the siblings involved, and has begun to unpack some of the complexities of these relationships in different cultural settings. Despite some challenges, the continuing development of culturally appropriate support remains vital. In particular, if confirmed by future research, alongside the need to explore means of reducing social stigma, a greater sharing of information around autism in Taiwanese families may be required, though with sensitivity to family systems and cultural values. More broadly, the themes that were identified in the present study as contributing to siblings' adjustment outcome are potentially important for health and educational professionals working with families of children with autism in the two cultural contexts.

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Table 1. Background information on participants

Taiwanese families	Age (years)		Gender		Diagnosis	No. children	Mother's employment	Autism Severity [b]
	Autism	Sibling [a]	Autism	Sibling				
TW 1	16.21	14.46	M	F	Asperger	2	Full-time	78
TW 2	5.46	10.25	M	F	Autism	3	Not Working	57
TW 3	12.40	17.22	F	F	Autism	3	Full-time	80
TW 4	12.78	10.80	M	M	Autism	2	Full-time	76
TW 5	18.22	13.21	M	F	Asperger	4	Not Working	90
TW 6	12.79	9.74	F	M	Asperger	2	Full-time	90
TW 7	15.89	14.35	M	F	Autism	2	Not Working	76

UK families	Age (years)		Gender		Diagnosis	No. children	Mother's employment	Autism severity [b]
	Autism	Sibling [a]	Autism	Sibling				
UK 1	13.78	12.24	M	M	Asperger	2	Full-time	74
UK 2	7.59	10.97	M	M	Asperger	3	Not Working	74
UK 3	8.95	11.18	M	F	Autism	3	Part-time	90
UK 4	6.69	9.11	M	M	Autism	2	Not Working	74
UK 5	10.27	11.86	M	M	Autism	4	Part-time	89
UK 6	5.07	10.27	M	F	Autism	4	Full-time	69
UK 7	15.14	13.14	M	F	Asperger	2	Part-time	80

[a.] In families with multiple siblings, the typically developing sibling closest in age to the child with autism was invited to participate.

[b.] Severity of symptoms in the child with autism, measured with The Social Responsiveness Scale, 2nd Edition (SRS-2; Constantino, 2012). Higher scores indicate more severe symptoms.

Figure 1. Theme 1: The influence of autism (and related subthemes)

Taiwan   UK

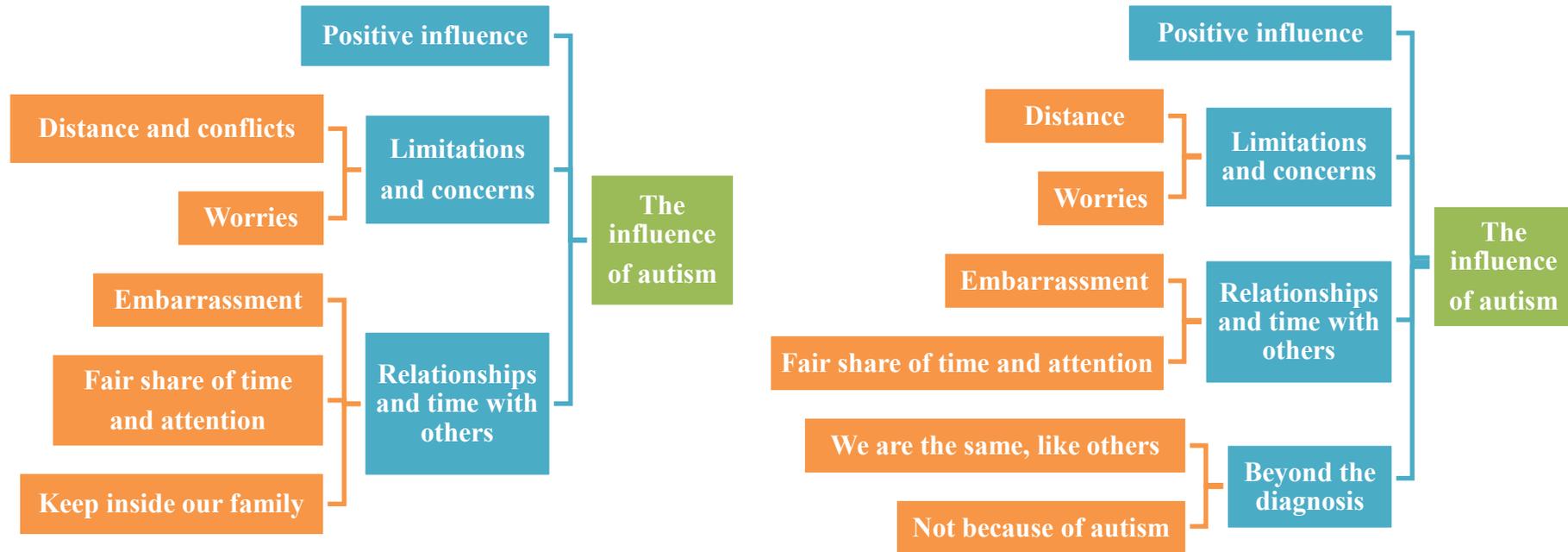Figure 2. Theme 2. Family resilience (and related subthemes)

Taiwan   UK

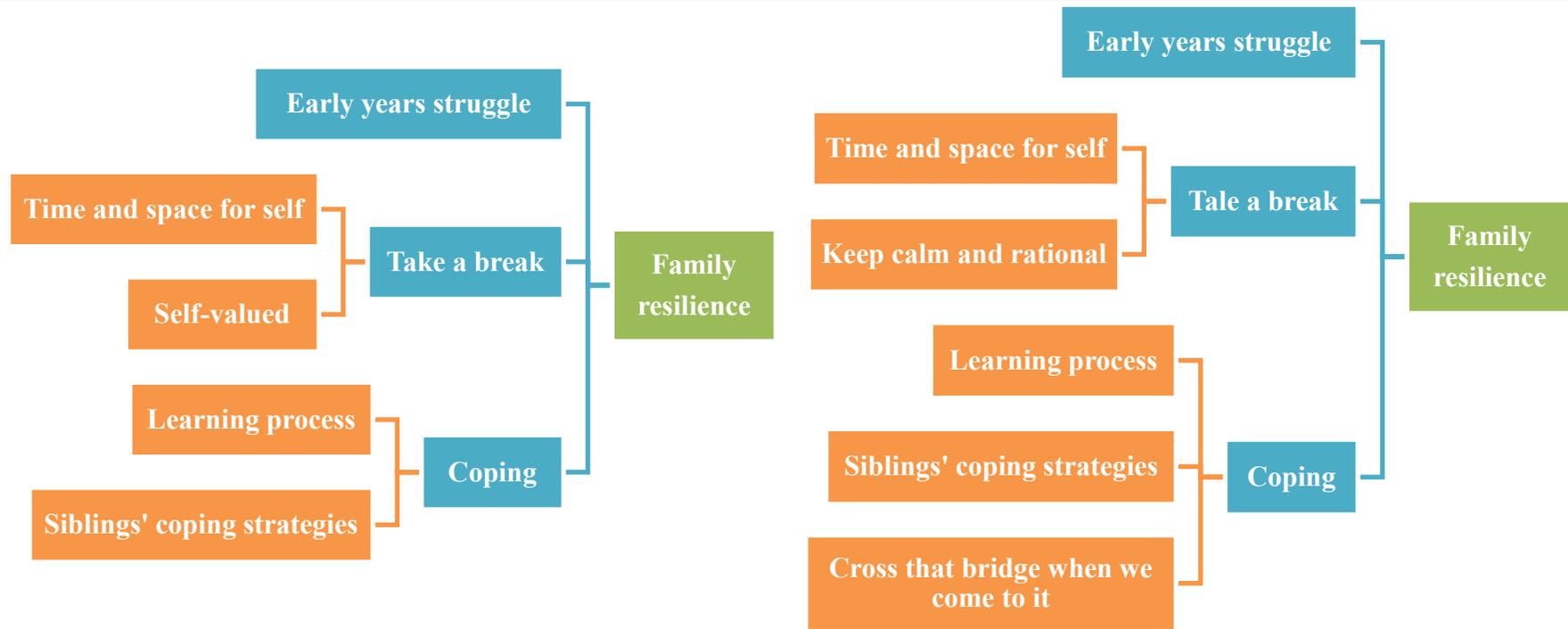Figure 3. Theme 3. What we do as a family (and related subthemes)

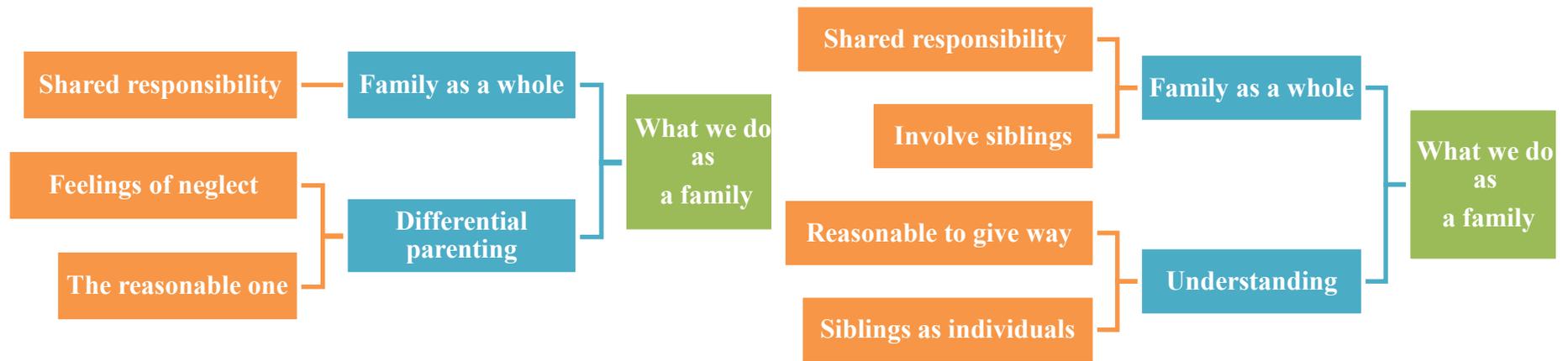Taiwan   UK

Figure 4. Theme 4. The support needed (and the related subthemes)

Taiwan   UK