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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

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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)

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