

Wellbeing of mothers of children with “A-U-T-I-S-M” in Malaysia: An interpretative phenomenological analysis study

Kartini Ilias, Jeanette Hui Jean Liaw, Kim Cornish, Miriam Sang-Ah Park & Karen Jennifer Golden

To cite this article: Kartini Ilias, Jeanette Hui Jean Liaw, Kim Cornish, Miriam Sang-Ah Park & Karen Jennifer Golden (2017) Wellbeing of mothers of children with “A-U-T-I-S-M” in Malaysia: An interpretative phenomenological analysis study, *Journal of Intellectual & Developmental Disability*, 42:1, 74-89, DOI: [10.3109/13668250.2016.1196657](https://doi.org/10.3109/13668250.2016.1196657)

To link to this article: <https://doi.org/10.3109/13668250.2016.1196657>



© 2016 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



Published online: 20 Jul 2016.



Submit your article to this journal [↗](#)



Article views: 4034



View Crossmark data [↗](#)



Citing articles: 6 View citing articles [↗](#)

Wellbeing of mothers of children with “A-U-T-I-S-M” in Malaysia: An interpretative phenomenological analysis study

Kartini Ilias^{a,c}, Jeanette Hui Jean Liaw^a, Kim Cornish^b , Miriam Sang-Ah Park^a  and Karen Jennifer Golden^a 

^aJeffrey Cheah School of Medicine and Health Sciences, Monash University Malaysia, Bandar Sunway, Selangor, Malaysia; ^bSchool of Psychological Sciences, Faculty of Medicine, Nursing, and Health Sciences, Monash University, Melbourne, Australia; ^cDepartment of Basic Sciences, Faculty of Health Sciences, Universiti Teknologi MARA, Puncak Alam, Selangor, Malaysia

ABSTRACT

Background This qualitative study aimed to explore how mothers gave meaning to their experiences of raising a child with autism spectrum disorder (ASD) in Malaysia.

Methods Using interpretative phenomenological analysis, semistructured interviews were conducted with 8 Malaysian mothers from different ethnic backgrounds (4 Chinese, 3 Malays, and 1 Indian).

Results Three themes for the mothers' adaptation and wellbeing development were identified, including Problem realisation within the context: Learning to spell A-U-T-I-S-M in Malaysia, WE are living with autism, and Resilient overcoming: Climbing Mount Kinabalu. The mothers viewed their child's ASD symptoms and behaviour problems (e.g., hyperactivity and sleep difficulties) as taking a toll on wellbeing. However, coping strategies, including acceptance, proactive mindset, character growth, spirituality, and parent support networks, fostered wellbeing.

Conclusion Both intrapersonal and interpersonal protective processes were important. The findings suggested that Seligman's (2011) PERMA framework may be applicable to understanding parental wellbeing. Clinical, policy, and research suggestions were discussed.

KEYWORDS

ASD; culture; wellbeing; qualitative; Asian; Malaysia; parent; resilience

Introduction

Approximately 52 million cases of autism spectrum disorder (ASD) have been reported globally (Baxter et al., 2015). Problematically, however, limited research has examined ASD within developing, low-to-middle income, and non-Western countries (Daley, Singhal, & Krishnamurthy, 2013; Freeth, Milne, Sheppard, & Ramachandran, 2014). In Malaysia, a developing, middle-income country with a multi-ethnic population comprised of three ethnicities as well as indigenous tribes, very limited awareness and support resources for raising a child with ASD are available (Clark, Brown, & Karripaya, 2012; Neik, Lee, Low, Chia, & Chua, 2014; Toran, 2011). In such a context, more information is needed in order to translate research into practice and to foster wellbeing and culturally informed evidenced-based treatments.

Parents of children with ASD: Stress and challenges

In the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.; *DSM-IV-TR*, American

Psychiatric Association, 2000), the category of pervasive developmental disorders included autistic disorder. Autistic disorder diagnostically involved a combination of qualitative impairments in reciprocal social interaction, communication, and repetitive, restricted, and stereotyped patterns of behaviour, with onset before or at 3 years of age (*DSM-IV-TR*, American Psychiatric Association, 2000). The *DSM-5* (5th ed.; American Psychiatric Association, 2013) classified ASD as a single umbrella category, replacing the four different subtypes in the *DSM-IV-TR*. Comorbidity between ASD and symptoms of other neurodevelopmental disorders, psychiatric conditions, and health problems have been demonstrated (Mannion, Brahm, & Leader, 2014), such as with attention-deficit/hyperactivity disorder (e.g., Cornish & Wilding, 2010) and sleep disorders (e.g., Mannion & Leader, 2014).

These comorbid symptoms along with primary ASD symptoms have been shown to significantly affect the quality of life of both persons with ASD and their families (e.g., Gardiner & Iarocci, 2012). As a result, ASD has been found to affect the family system both positively and negatively (e.g., Cridland, Jones, Magee,

CONTACT Karen Jennifer Golden  karen.golden@monash.edu

© 2016 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

& Caputi, 2014). Much research has highlighted the difficulties experienced (e.g., Hayes & Watson, 2013), and a small, but growing body of research has sought to understand the strengths, wellbeing, and resiliency of these parents as well (e.g., Bayat & Schuntermann, 2013).

Past research indicated family functioning impairments and elevated stress levels in parents of children with ASD (e.g., Hayes & Watson, 2013); parents often reported difficulty dealing with their child's behaviour and emotional problems (e.g., Firth & Dryer, 2013; Herring et al., 2006; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014). Mothers of children with ASD particularly were often found to play the primary caregiver role (e.g., Braunstein, Peniston, Perelman, & Cassano, 2013) and reported higher levels of depression and stress than fathers (e.g., Davis & Carter, 2008; Hastings, Kovshoff, Brown, et al., 2005; Herring et al., 2006). The impact on mothers may be especially strong in traditional societies. Maternal stress and wellbeing may also be affected by paternal factors/paternal wellbeing and vice versa (e.g., Hastings, Kovshoff, Ward, et al., 2005), although research on this interaction is limited.

Parental adaptation and wellbeing

Research reported that families of children with ASD can demonstrate positive adaptation and wellbeing. For example, much past research used the double ABCX model framework to study families of children with ASD (e.g., Manning, Wainwright, & Bennett, 2011). Hill's (1958) ABCX family crisis model was expanded to the double ABCX model by adding postcrisis variables in an attempt to describe life stressors, family resources, and the meaning of the event over time (McCubbin & Patterson, 1983). Findings using this framework have suggested that families may face initial stressors such as the severity of ASD symptoms as well as an accumulation of other stressors such as illness, divorce, or job loss that may not relate to ASD directly, but intensify the effects of the strain caused by ASD (e.g., Manning et al., 2011).

The model proposed that family adaptive resources, such as social support, can lead to successful coping (e.g., Manning et al., 2011). Furthermore, the family's perceptions or the meaning they give to the crisis situation can lead to reframing, which has been linked with lower levels of depression in parents of children with ASD (Manning et al., 2011). Additionally, positive cognitions have been associated with parental resourcefulness and resiliency (Bekhet, Johnson, & Zauszniewski, 2012). The outcome of the model (the "X") represented family adaptation. The dynamic and ongoing nature of this model's adaptation process had significance to the

present study on wellbeing, which explored the applicability of this model to mothers of children with ASD in Malaysia.

It should be noted that the term *wellbeing* has not been well defined in the broader literature (e.g., Dodge, Daly, Huyton, & Sanders, 2012; Ereaut & Whiting, 2008; Manderson, 2005), or in the ASD research field (e.g., Tint & Weiss, 2016). However, research has increasingly emphasised wellbeing as a multidimensional concept (e.g., Pozo, Sarriá, & Brioso, 2014), which goes beyond simply adapting and returning to baseline. For example, Seligman (2011) offered a new theory of wellbeing, describing wellbeing as *flourishing* and as a *construct* with five measurable elements with the acronym "PERMA," namely, *positive emotion, engagement, relationships, meaning and purpose, and accomplishment*. Seligman described that the PERMA domains fall on the positive side of the mental health spectrum and that wellbeing is not just the lack of negative psychological states (Seligman & Csikszentmihalyi, 2000). Garrod (2013) highlighted that when researching wellbeing, "in addition to Seligman's theory, it is important to understand how the PERMA model relates to the world in which each individual lives" (pp. 12–13), and to consider the social disadvantages and inequities in the environment.

Furthermore, researchers have highlighted that a contextual view is needed in order to understand wellbeing (e.g., McNulty & Fincham, 2012). For example, Manderson (2005) conceptualised wellbeing as both a social and individual phenomena. She stressed that the individual sense of wellbeing is embedded and derives from society, itself socially produced and sustained by social structures and systems. She discussed how conceptions of disability are socially produced. As Kwok and Wong (2000) described, the cultural context may play a role in the stress experienced by parents of children with ASD. Dyches, Wilder, Sudweeks, Obiakor, and Algozzine's (2004) study on the beliefs about ASD among parents from different ethnic groups found that "members of various cultures may appraise the stressor of autism differently, and these appraisals may be considered to be negative or positive" (p. 219). Although some ASD-related research has been conducted examining possible cross-cultural differences within Asia (e.g., DeLambo, Chung, & Huang, 2011; Jiar & Xi, 2012), culture-specific factors influencing mothers' experiences in different settings have not been examined in depth. Some recent qualitative studies have illuminated themes faced by parents of children with ASD in different regions globally (e.g., Cridland, Jones, Caputi, & Magee, 2014; Griffith, Totsika, Nash, Jones, & Hastings, 2012; Jardine, 2008; Phelps, Hodgson, McCammon, & Lamson, 2009;

Swanepoel, 2003), but limited qualitative work has been conducted in Malaysia (Ting & Chuah, 2010).

Wellbeing of parents of children with ASD in the Malaysian context

Research on parents of children with ASD has largely been limited to families in Western or developed countries (Daley, 2002; Freeth et al., 2014), but more recently, researchers have highlighted the importance of cross-cultural research (e.g., Daley et al., 2013; Norbury & Sparks, 2013). Given the limited ASD research in South-East Asia and in particular Malaysia, researchers have noted that there is a tremendous need for more investigation (e.g., Clark et al., 2012; Golden & Liaw, 2015; Ilias, Ponnusamy, & Normah, 2008; Neik et al., 2014). The Ministry of Health Malaysia (2011) has urged that more studies be conducted on children with disability and their caregivers. Construction of a national autism centre, Permata Kurnia, was recently completed, and study findings could inform policy development.

Regional studies have demonstrated high stress levels and elevated levels of depression in parents of children with ASD, but greater efforts to contextualise wellbeing development and resilience are needed. Nikmat, Ahmad, Oon, and Razali (2008) found that 53.8% of Malaysian parents of children with autism showed a clinical disturbance in psychological wellbeing, conceptualised as clinically elevated scores on the General Health Questionnaire (GHQ-28), and 90.4% of parents demonstrated significant parenting stress on the Parenting Stress Index – Short Form (PSI-SF). Comparatively, similar parenting stress mean scores were found in a recent quantitative study in Singapore (Lai, Goh, Oei, & Sung, 2015). Lai et al. (2015) utilised the Depression Anxiety Stress Scales (DASS-21) to measure the psychological wellbeing of parents, finding higher scores in parents of children with ASD than in parents of typically developing children. Lai et al. (2015) highlighted the paucity of research in parental wellbeing among Asian parents of children with ASD living in Asian countries. The results of their quantitative study emphasised the relevance of exploring culture-specific coping behaviours. Additionally, the use of qualitative methods to allow for more in-depth exploration of caregiving experiences has been strongly recommended (e.g., Lai et al., 2015; Lai & Oei, 2014).

Study rationale

Interpretative phenomenological analysis (IPA) was selected as an ideal qualitative research approach to explore wellbeing development in the Malaysian context

because of its suitability to topics where the aim is to understand how people perceive and understand significant life events (Smith & Eatough, 2007). Reid, Flowers, and Larkin (2005) highlighted that IPA is consistent with a positive psychology lens of wellbeing, giving participants a chance to express views about strength, wellness, and quality of life. Furthermore, Griffith et al. (2012) remarked about its suitability to family research about developmental disability, with populations for which little is known. Few studies specifically examined the phenomenological understandings of the wellbeing of mothers of children with ASD in developing countries. Past wellbeing research in Malaysia relied primarily on quantitative methods and utilised a narrow conceptualisation of wellbeing.

The present IPA study aimed to explore how mothers give meaning to their experiences of raising a child with ASD in Malaysia and to explore these mothers' experiences of adaptation and wellbeing development. We expanded beyond the double ABCX model (an extensively past researched framework to conceptualise adaptation), adding in the PERMA model, a more innovative framework to conceptualise wellbeing that has yet to be directly applied to parents of children with ASD. The study aimed to explore the mothers' experiences and conceptualisations of wellbeing in their own words, using these two past theoretical models as reference points to illuminate a contextual understanding of wellbeing in an underresearched context. This study also served as an exploratory, qualitative first phase of a broader, mixed-methods longitudinal project designed to develop a theoretical model of resiliency in parents of children with ASD.

Method

Participants

Eight mothers were recruited with flyers advertising the study in treatment centres, schools, and online ASD parent support groups. The study included mothers who had at least one son or daughter diagnosed with *DSM-IV-TR* autistic disorder by a registered mental health professional or developmental paediatrician; who lived in Malaysia for the majority of their lives; and who were raising their children in Malaysia. Seven interviews were conducted predominantly in English, although occasional comments occurred in the Malay, Mandarin, or Cantonese languages. One interview was predominantly in Malay.

The sample contained eight participants in this study, a number comparable to other published IPA studies, which often utilise a very small number of homogenous

participants (Griffith et al., 2012; Smith & Osborn, 2003). Such a sample allowed for a detailed examination of similarities and differences as well as sufficient in-depth ideographic engagement with each case. Two potential participants were excluded (not interviewed) in this study phase because their children had a different ASD diagnosis (Asperger's disorder). The choice to focus first upon autistic disorder recognised the greater clear-cut challenges these mothers likely faced, as their children often required more support services. All names have been changed to pseudonyms to protect privacy.

Demographics

Four of the eight mothers had a Chinese ethnic/cultural background, three a Malay background, and one mother an Indian background. They were all living in the Klang Valley, an urban/suburban region including the capital city Kuala Lumpur and surrounding areas. The mothers were aged between 32 and 59 years ($M_{\text{age}} = 43.5$ years). Ethnic, religious, employment, marital status, and income factors are illustrated in Table 1. The mothers had a total of 10 children (nine boys, one girl) diagnosed with *DSM-IV-TR* autistic disorder. They were between the ages of 5 and 23 years. ($M_{\text{age}} = 11.0$ years; see Table 2). Six participants lived in urban areas; two participants (Mila and Halina) lived in suburban areas on the outskirts of the city, about a 45–60 minute drive from the city centre area.

Design

The study utilised an IPA qualitative design and analysis. The theoretical underpinnings of IPA stemmed from phenomenology (originating with Husserl's attempts to construct a philosophical science of consciousness), hermeneutics (the theory of interpretation), and symbolic-interactionism (positing that the meanings an individual ascribes to events are of central concern but only accessible through a process of interpretation; Biggerstaff & Thompson, 2008, p. 215). In IPA, the researcher tries to achieve a balance between listening empathetically to

participants' experiences and asking critical questions of the data for deeper understanding and interpretation (Smith & Eatough, 2007). No formal hypotheses were formulated in this exploratory study, as IPA avoids prior assumptions and does not aim to test hypotheses (Reid et al., 2005).

Procedure

Recruitment strategy

Ethical approval was received from the Monash University Human Research Ethics Committee (CF12/1611–2012000868). The researchers developed collaborative partnerships (e.g., see Daley et al., 2013) with ASD-related organisations by initiating contact with centre administrators (e.g., The National Autism Society of Malaysia) via email and phone. Several organisations responded and provided written permission, agreeing to post advertisements. In-person meetings were also held with organisations. Hardcopy and online flyers were posted in ASD centres, schools, and online parent support groups. Interested mothers then contacted the researchers through phone or email and participants' questions were clarified. Prospective participants were screened to ensure they met the inclusion criteria by the research supervisor, a licensed clinical psychologist (in California and Malaysia) trained in ASD diagnostic assessment. After the interview, participants were given a shopping voucher as a token of appreciation, equivalent to US\$10.00.

Interview process

A psychology postgraduate student researcher conducted the semistructured face-to-face interviews. Another postgraduate student (who is a locally registered clinical psychologist) observed the sixth and seventh interviews. The primary research supervisor for both students observed the second and fifth interviews. The in-depth interviews lasted between 75 to 120 minutes. All participants read a statement describing the study,

Table 1. Demographics of mothers of children with ASD.

Participant	Age range	Race/ ethnicity	Religion	Marital status	Level of education	Employment status	Personal monthly income (RM)
Nancy	50–60	Chinese	Christian	Married	High school	Part-time freelancer	3,000–5,000
Lilian	40–50	Chinese	"Free thinker"	Married	Foundation/pre-university	Part-time freelancer	5,000 and above
Winnie	50–60	Chinese	Christian	Divorced	High school	Part-time	Below 3,000
May Lin	40–50	Chinese	Christian	Widowed	Bachelor's degree	Housewife	Below 3,000
Amina	30–40	Malay	Muslim	Married	Master's degree	Student	5,000 and above
Shirin	30–40	Indian	Christian	Married	Diploma	Housewife	3,000–5,000
Mila	30–40	Malay	Muslim	Married	Master's degree	Housewife	Below 3,000
Halina	40–50	Malay	Muslim	Married	Bachelor's degree	Full-time office work	3,000–5,000

Note. Currency conversion rate – USD1 (US\$1.00) – equalled approximately Ringgit Malaysia RM3 at the time of the study. According to the Department of Statistics Malaysia (Jabatan Perangkaan Malaysia) (2014), the 2013 Household Income Survey showed that the mean household income nationwide was RM5742 (urban areas) and RM3080 (rural areas). All names have been changed to pseudonyms; mothers' individual ages are reported in 10-year intervals.

Table 2. Details of the child(ren) with ASD of each mother.

Mothers	Child(ren)	Child(ren)'s age (years), gender	Age diagnosed	Number of people in household	Child(ren)'s school type
Nancy	Aaron	23, male	2.5 years	5	Primary education was in a typical government school. Following difficulties finding a secondary school, began home schooling until the present. Part-time tutor comes to the home.
Lilian	Billy	6, male	3 years, 2 months	4	Private mainstream Montessori kindergarten (weekday mornings).
Winnie	Chip and Clark	18 and 15, both male	2 years, 9 months; 2 years, 0 months	5	Full-day (5.5 hours) special education classroom in local government school.
May Lin	Mulan	11, female	2 years	4	Private non-profit school (children with diverse special needs).
Amina	Amir	6, male	3 years, 10 months	4	Non-profit kindergarten-primary multidisciplinary special needs school (weekday mornings).
Shirin	Mohan	6, male	2 years, 11 months	4	Afternoon part-time playschool at the local religious institution.
Mila	Alif and Arif	8 and 5, both male	2 years, 9 months; 4 years, 5 months	5	Full-day (5.5 hours) special education classroom in local government school.
Halina	Aidid	12, male	3 years	6	Full-day (5.5 hours) special education classroom in local government school.

Note. All names (mothers and children) have been changed to pseudonyms. The age of diagnosis reported in the time intervals was identified by the mothers themselves (i.e., months or years).

signed a written consent form and completed a demographic questionnaire before the interview. Interviews were conducted in convenient locations (e.g., mothers' homes/offices, quiet treatment centre room). Broad open-ended questions were employed (see interview guide, Table 3). Interviews were digitally audio-recorded and manually transcribed verbatim by the student researchers, translated into English when needed, and checked for accuracy by the supervisor.

Data analysis

The interview transcriptions formed the basis of the interpretative data analysis, along with reference to the reflexive diaries/journals (see Smith, 2003), which included notes from screening calls, notes taken during the interview and related nonverbal observations, notes from communications with community organisations, and reflections during study planning, data collection,

and analysis. The NVivo 9 data management software was used. Before starting analysis, each participant's transcript was read in detail to get an overall "feel." Then, concise phrases representing units of meaning that captured the essential quality of a particular text in the transcript were coded initially by the student researcher. These units were grouped and identified as categories and emerging themes. In accordance with the traditional IPA approach, all transcripts were first individually analysed before the identified themes were considered together as a whole to form an overall group analysis, and organised into interconnected hierarchies (i.e., themes, subthemes, and categories). This analysis approach exemplified IPA's aim of valuing participants' individual experiences.

To increase trustworthiness and check for coding accuracy, the research supervisor reviewed the student's initial units of meaning codes for all eight interview transcripts. Coding consistency between student and supervisor was high for these codes, approximately 95% agreement (i.e., 5% of the time the supervisor did not agree with the student's unit of meaning codes or the labels assigned to these codes). Discrepancies were reviewed and consensus reached before proceeding. Additionally, a qualitative researcher independent of the project reviewed unit of meaning coding for one transcript and reviewed the themes/subthemes for the overall sample, providing general comments and suggestions. The supervisor also reviewed the themes/subthemes. Consensus was obtained within the research team, agreeing on the final codes and the themes, subthemes, and categories.

Table 3. Interview guide, questions and prompts.

1. Please begin by telling me about your experience of having a child with autism.
2. Based on your experiences of raising a child with autism, what experiences have been most meaningful to you?
 - a. How do you understand the meaning of having a child with autism?
3. Tell me about any challenges, if any, that you have faced raising your child with autism or being a mother to a child with autism.
4. Tell me about what has helped you in the process of raising him/her. Tell me about what has helped improve your wellbeing.
 - a. Tell me about what or who has helped or supported you.
 - b. How have you coped with having a child with autism?
5. Tell me about your experience of having a child with autism in your family.
6. Tell me about the experience of being a mother to a child with autism in Malaysia and in your culture.
7. If you could provide advice or suggestions to other mothers with a child with autism in Malaysia, what would it be? What advice or suggestions would you give to other mothers to help improve their wellbeing?
8. Please let me know any other comments that you have about this research topic. Please let me know any questions that you have about this research.

Results

The findings included themes in three main overarching areas (see Table 4) identified through IPA data analysis

Table 4. Themes, subthemes, and categories.

Themes	Subthemes	Categories
Problem realisation within the context: Learning to spell A-U-T-I-S-M in Malaysia	Autism as a voyage	The process of diagnosis Awareness of ASD in the society Cultural/lay beliefs on autism
	Lack of resources/need for more governmental support	Schools Therapeutic services Financial aid Employment for those with ASD
	Worries for the future	
WE are living with autism	Impact on family	Family system quarrels Mothers as primary caretakers and fathers' lower level of involvement Father's denial/acceptance process Nuclear family support Supportive extended family
	The toll on wellbeing	Daily challenges of autism and behavioural symptoms Lonely journey: Reduced social life Mixed emotions
Resilient overcoming: Climbing Mount Kinabalu	Coping strategies: Changed lives	Change in character Empowered to be proactive Acceptance and purpose Shifting of parental expectations Spiritual beliefs
	We support each other: Community support ASD in the globalised internet age	

(Smith & Osborn, 2003). The first theme described *Problem realisation within the context: Learning to spell A-U-T-I-S-M in Malaysia*, illustrating the process of diagnosing and identifying ASD and related challenges within the Malaysian context. The second theme, *WE are living with autism*, included how the mothers gave meaning to their collective experiences raising a child with ASD in their family. The third theme, *Resilient overcoming: Climbing Mount Kinabalu*, described the coping and adaptation processes fostering wellbeing and flourishing in these women.

Theme 1. Problem realisation within the context: Learning to spell A-U-T-I-S-M in Malaysia

Autism as a voyage

The significance of autism as a voyage was a strongly featured subtheme by all eight participants.

The process of diagnosis. This stage represented the start of the voyage. Seven of the eight mothers described recognising themselves that their child did not behave in a manner typical of other children. The children displayed difficulties interacting with their environment in terms of delayed speech, social difficulties, self-harm behaviours, and sensory sensitivities. The mothers of boys reported an experience similar to Amina: "I had the instinct but still everybody seems to say that it's nothing. He's a boy."

The participants then talked about their diverse experiences of the formal diagnosis process, which

occurred approximately a year or two after recognising abnormalities. Two of the participants shared that they did not meet health professionals for the diagnosis of autism, but for alternative reasons. Other mothers reported undergoing general diagnostic procedures in local hospitals. Four mothers recounted being "puzzled," not knowing at all what "autism" was:

I didn't know she has autism until she got a fever. I sent her to the hospital. Then the doctor suspected that she is having autism. I said, "What is autism?" Then he said this is a lifelong thing. Then I asked, "Doctor, how to spell?" He said, "A-u-t-i-s-m." (May Lin)

The voyage towards a diagnosis occurred within the context of low awareness of ASD in society. Although diagnosis occurred at a relatively young age, intensive interventions and appropriate schooling were delayed for all participants, secondary to the difficulty finding available and affordable resources.

Awareness of ASD in the society. All eight mothers shared their experiences of the limited awareness of ASD in the Malaysian society, which they perceived as less than in the West, and less than even in neighbouring countries like Singapore and the Philippines. Although Mila did mention that awareness is gradually "getting better ... back in 2009, it was very difficult, nobody knows, even the teachers have problems understanding autism." Society's lack of knowledge led the mothers to be judged negatively as bad parents, and the child with

ASD was perceived and labelled as “naughty” (Shirin) or “not-disciplined” (Winnie). Nancy explained, “We told the doctor he’s autistic, the doctor was blank, and so we have to explain what is autism. I’m surprised that even a doctor doesn’t know.” Although struggles of awareness are a common challenge facing all parents, even in developed countries, the degree of poor understanding and support was described as very pervasive in Malaysia.

Cultural/lay beliefs on ASD. This inadequate knowledge led people in the society to rely on cultural and lay beliefs to explain the disorder’s cause. Six participants from different religious backgrounds reported being exposed to traditional cultural beliefs:

To people like my eldest sister, it could be because we did something wrong in our previous life. This is a traditional Chinese belief ... The older people say that in my past life, I owe him [Aaron] a debt because of the things that I’ve done, so now he has come back to claim what I owed him. (Nancy)

In the Chinese culture ... it could be the earlier generation has done something, so now it’s like paying back or something. (Winnie)

Mohan is the only Indian in his school, you ask teachers and they will tell you that the Indian community doesn’t come, they’re very afraid. They’re always in the house, they keep the child in the house ... I think they’re afraid because they have too much knowledge about magic and witchcraft ... They try to find witchdoctors [for cure]. (Shirin)

In the Malay culture ... they think that maybe there’s something like this mystic thing, like a ghost or something, some spirit is following him somewhere and disturbing him. Like maybe we have to remove him from his “buddy” because he’s not talking. My mother and father-in-law believed in that ... They said maybe I stepped on something, maybe I went to a remote area or some place that people don’t go, so there are ghosts in there, or I might have killed some animal. Like the Malay say “badi.” So if you do something bad with your husband while you are pregnant, there’s a tendency that your pregnancy, your baby, will carry something bad. (Mila)

Notably, the mothers’ comments centred upon culturally transmitted fears and concerns that they may have done something wrong in the past to cause the disorder. Although they seemed not to believe these traditional beliefs themselves, the mothers described these societal perspectives as stigmatising.

Lack of resources/need for more governmental support

All mothers shared their realisation of the need for more support from the government in terms of more special schools for their children, therapeutic services, financial

aid, and employment opportunities. The mothers residing more on the city outskirts faced more challenges finding resources.

Schools. All mothers reported challenges “finding schools” and dealing with private and/or government schools.

Seven sets of kindergarten uniforms, but I think the kindergartens were more than seven. Because after so many years, so much money wasted, I told the principal, you try her out, 2 weeks. If you think you can take her, I will buy the uniform. (May Lin)

Moreover, parents reported that teachers did not demonstrate appropriate knowledge and care in handling students with ASD, even to the point of using inappropriate discipline. However, as May Lin explained, “Because resources are limited, we cannot confront anyone. We have to swallow our anger. We just keep quiet sometimes because we have no place to turn to, no place to go.” Mila lamented the mixing of many kinds of children with special needs together into one “special class” in government schools: “the teachers are lost to understand.” The mothers advocated the benefits of educational inclusion policies:

I absolutely hope that children with autism, those mild or moderate, are given the opportunity to be included in the mainstream class. But the support must be there ... they need to have awareness, not only mothers alone, but teachers. (Lilian)

Therapeutic services. All eight mothers also complained about the lack of therapy services and treatments for children with ASD in Malaysia. Two mothers described that there is a need for “one-stop centres,” to save time and energy when getting multiple treatments:

Actually we need a lot of therapies. Our government has therapies, but there’s a long waiting list. They should have more. (Nancy)

The therapists were not really helpful in terms of experience. They don’t have enough experience for early intervention treatment. (Amina)

One mother took the route of alternative, nonevidenced-based treatments out of desperation to help her child (e.g., “chelation”). Chelation, which carries the risk of serious side effects, involves administering chelating agents to remove heavy metals from the blood (Davis et al., 2013). Moreover, three mothers emphasised the perceived direct benefits of dietary treatments on their children’s behaviour, which also led to perceived improvements in parental wellbeing.

Financial aid. Nancy stated that the lack of needed therapies gave her no choice but to seek the assistance of private

therapists, which were “getting more expensive.” Six participants directly mentioned significant financial problems because of the costs of private therapies:

I think money is a main issue in bringing up an autistic [sic] child. (Nancy)

Financially [I'm] also affected greatly ... all my money I save, all for her treatment. (May Lin)

We couldn't afford the private school with ABA [applied behavior analysis therapy], it's quite expensive. (Shirin)

Employment for those with ASD. Lastly, three mothers reported they desired more help from the government in providing their child with employment or a platform for their talents. Nancy worried: “There are special kids who work, but they get bullied. They're forced to work extra hours. People take advantage of them.”

Worries for the future

Four of the mothers directly expressed concerns and “worry” about their child's long-term future. The mothers feared that their children would not be able to find work to support themselves and be “independent.” Halina lamented, “What is going to happen to him in the future!” Lilian remarked: “This is probably the research that needs to be carried out for [their] future support.” The mothers' experiences and fears even led them to try to migrate abroad: “I wanted to migrate to Australia. Many professionals with children with special needs left Malaysia because there's no support from government. There's no facilities for these children, there's no future for them.” May Lin was especially concerned for her daughter's wellbeing and safety after hearing problematic stories of young women with special needs experiencing sexual abuse.

Theme 2. WE are living with autism

After diagnosis and realising the problems they faced, all eight mothers were confronted with the task of adapting to the positive and negative impacts of having a child with ASD in the family. This theme captures the collective (“We”) experiences and attitudes of the mothers and family members in “living with autism” and describes the perceived toll taken on the women's wellbeing.

Impact on family

For all participants, living with a child with ASD had a tremendous impact on family members.

Family system quarrels. “It affects family and sibling relationships.” Family conflicts placed a heavy burden on five mothers. For example, Shirin described:

It's very difficult because a lot of the decision-making depends on me. I'm very firm sometimes, if I have to fight for it, I'll fight for it and that might cause people to be angry and not happy. So there are a lot of issues involved when it comes to my husband and I.

Conflicts seemed to arise from perceived caregiving role imbalances, differing acceptance levels, and mostly from stress and fatigue dealing with behavioural challenges. This additional quote illustrates the complex family system issues experienced:

My husband and I always quarrel because my daughter [with autism] can wake up five times a night everyday ... Sometimes I also feel very sorry for my son ... Sometimes my son [without autism] will say, “Mummy, you don't ask me to look after sis, I'm very tired.” If possible, I don't want to burden him. (May Lin)

Family disharmony occurred not just between a child with typical development and his or her sibling with ASD (e.g., “jealousy,” Halina), but conflict also happened between both siblings with ASD. Winnie also faced an even worse experience during her marriage as her ex-husband used their children with ASD as an excuse “to blame me” and end the marriage.

Mothers as primary caretaker and fathers' lower level of involvement. All mothers reported, like Nancy, “Most of the time I'm the only one handling him.” They shared a relative lack of involvement from the fathers in caring for their child(ren) with ASD. Amina explained: “Sometimes I'm the only caretaker of my children, so I'm too tired and then added with house chores and everything. They're contributing factors to my arguments with my husband.” Most fathers were usually “busy working” to provide needed financial support. Unfortunately, May Lin and Mila mentioned with frustration that their husbands seemed to have little interest to learn in-depth information about their child's condition.

Father's denial/acceptance process. Five of the mothers reported that their husbands struggled to accept their child's condition initially. Four participants mentioned the perception that their husbands were in a state of denial for a long time (longer than the mothers). Mila shared: “I think the acceptance from the mothers is maybe better compared to the husbands. It takes a long time until, I think only recently, he can accept. The acceptance is later compared to me.” Amina illustrated how this affected intervention:

The treatment progress is very slow, because at that time, I need to convince my husband that his son is not going to be okay. They cannot, I think most spouses, they have this grieving or in denial stage. That stage, really wasted my time, wasted my son's time.

Nuclear family support. Participants shared fewer positive than negative experiences with nuclear family members. However, they still all described how immediate family members supported them emotionally and helped them, especially later when acceptance of the condition grew and the family system adapted and reorganised to meet the members' needs. Positive changes were observed over time, as Halina shared: "Actually the one who really supported me is my husband. He is very open towards it, and he's more accepting of it now." Mila's quote illustrated the change over time: "He (husband) is more participative in doing things with the children [two boys with autism]. He's learning more and he's educating his office colleagues." Participants also shared their experiences of the support provided by their children without ASD. Additionally, three mothers directly described their child with ASD being "attached"/"close to the family" and generally having a "good relationship" with the family members, which fostered family-level wellbeing.

Supportive extended family. Seven of the participants mentioned that extended family members were a source of strength for them. Some helped financially, whereas others provided emotional or physical support, such as helping with cooking/childcare:

I got support from my family, my sister, my mother.
(Amina)
Aidid's grandparents do try to adjust to him. They even try to speak in English with him. (Halina)

However, for one participant, in-laws were a source of great stress, harshly blaming her for the condition and even threatened to "build a cage" to put her child inside.

Toll on wellbeing

Despite some supports, all mothers reported that having a child with ASD took a toll on their wellbeing.

Daily challenges of autism and behavioural symptoms.

All the mothers revealed their worries, concerns, and difficulties handling their child's symptoms of autism, and all cited other frequent behavioural problems as well: "When he was younger, he not only had autism but was also hyperactive ... It's actually a lot of things that we went through." The problematic symptoms included communication problems, being "in a world of his own," "sleep problems," "hyperactivity," tantrums, toileting/self-care difficulties, aggression/breaking items, learning difficulties, and picky eating.

Lonely journey: Reduced social life. For three mothers, the reduced social life was much more apparent

compared to the other five mothers who mentioned it more in passing. Behavioural difficulties in going out socially led to choosing to focus more time on the nuclear family, rather than externally. For example, May Lin commented that because of the lack of social support and "cutting down on a lot of social activities," the journey of raising her daughter became a "lonely journey" associated with feeling "depressed," secondary to her sense that she "cannot live like a normal person." For May Lin, she grew to find gratification through her time-intensive role and identity "teaching" her daughter. Similarly, Amina described slowly learning to accept new restrictions:

I have not met up with my friends for a long time, like my older friends. Just SMS [phone text messaging], WhatsApp [an instant mobile smartphone messaging application], that's all. But I don't have any intention to see them ... I miss them, but I accept it.

Mixed emotions. Given the hardships experienced, it is not surprising that quite a number of mothers (six) reported feeling "sad," "worried," and "depressed," especially initially. In a sombre tone, Nancy reported feeling, "Mentally, physically, and emotionally tired ... My wellbeing has deteriorated!" Winnie elaborated: "At first I was very sad, but sad also no use. So got to be very patient." When asked to describe the experience of raising her child with autism in Malaysia, one participant responded, "It's very depressing. It's like going to hell. Serious. We have to help ourselves." Although negative feelings were experienced, so were positives by all mothers:

Nancy: Of course he brings joy sometimes when I can see and accept him as he is. You can see sometimes even normal kids can be worse than him. He brings joy and sadness. Sometimes he's very loving, and he's always my companion.
Researcher: How have you coped with having a child with autism?
Nancy: Whether I like or don't like, have to cope.

Theme 3. Resilient overcoming: Climbing Mount Kinabalu

Despite some positive feedback about growing community support, all of the mothers expressed their dissatisfaction with the limited resources. From interpreting the mothers' experiences emerged the metaphor of *Climbing Mount Kinabalu*, which is Malaysia's highest peak (Ruhazad, 2013). Symbolically, climbing the mountain was a "tiring" voyage, but contained moments of "joy," especially at times of "breakthrough," "progress," and

“accomplishment.” To reach the summit necessitated a resilient, “tough” fighting spirit and adequate preparation. They did not know whether they would be able to reach the summit and became sad and depressed initially. They resiliently persevered to overcome challenges, find solutions, and kept climbing. They maintained faith that sooner or later they would reach the peak. May Lin emotionally asserted, “I say if you have the heart, you will find a way.”

Coping strategies: Changed lives

Despite challenges, the mothers utilised various coping strategies. These strategies had a positive impact, strengthening them to work diligently and strive harder. When asked to explain the meaning they found in their situations and what fostered their wellbeing, they noted several different processes occurring.

Change in character. For Nancy, she not only developed a better attitude but also changed to be more assertive and protective: “We also experience a change in character. Change to be good, understanding, accepting people, and more patient. But I also became more defensive; we have to fight for our kid because they cannot talk. We have to be thick-skinned.” Amina re-evaluated her life priorities:

Now the priority will be my son. After everything, I think I can see which one matters most between career and family. At the moment, I see all these things as very meaningful to me. After this experience, I can see that I’m more flexible, more open-minded ... My life pace slowed down, appreciate everything around me.

Halina explained in more detail: “Since we cannot change people, we have to change ourselves to become more positive. We try to form our inner side, my inner side with the support of my spouse and family. I try to feel more positive about the situation.”

Empowered to be proactive. Seven mothers strongly conveyed a sense of being “proactive” to help their children. Additionally, all of the mothers desired to fully engage and “put in the effort” needed. The majority of mothers mentioned getting information about ASD from books, the internet, and seminars soon after finding out that their child had autism. Amina stated that despite the minimal facilities in Malaysia, she still managed to cope by actively searching for therapies that suited her child best, even flying in professional experts from the West. May Lin and Lilian also mentioned that there is a need to be “proactive” and take “initiative” for their own wellbeing. Mila summarised:

If you don’t have the financial means for it, you can do it at home, if you are willing. This is your child, no one else’s child. You can do it by playing with the child

and all that ... Through knowledge, through asking people questions, that’s where you start that first step to know what is that six letter [a-u-t-i-s-m], what it stands for, what is the purpose, what is life going to be? All these questions you’ll have to find out answers.

Acceptance and purpose. The mothers (six) also explicitly described a process of “accepting” their child with autism for who they are as a form of coping. Acceptance seemed to occur naturally as mothers developed a deeper relationship and love for their child. Some mothers also found it easier to accept, after considering that there might be a greater purpose:

I always believe that there’s a purpose to have a child like Aaron. (Nancy)
There must be a reason why we’re God’s chosen ones. Because I think I’m the most suitable person who can take care of these special kids ... Raising my special child made me realise that, we have to move forward. Don’t think about the problem. Just find the solution. (Amina)

Shifting parental expectations. Five mothers directly spoke of readjusting their “expectations” for their child’s future and life achievements. The mothers reported experiencing better wellbeing and joy from their child’s accomplishments after they lowered their expectations.

I’m no longer like a lot of parents, like what they call “kia su” (prideful). I think that I don’t expect him to achieve excellence in an academic way. I lowered down my expectation. I hope that he can live an independent life on his own. That is what I’m aiming for. At this moment, I’m happy with whatever bonus that I get. (Lilian)

The mothers were “content,” “comforted,” and “happy,” even with small accomplishments, and reported learning how to “go with the flow.”

Spiritual beliefs. The participants’ sense of purpose for having a child with autism often related to their religious beliefs. All of the mothers described that spirituality and religion was a support and encouragement for them in times of difficulty: “The spiritual aspect helps a lot” (Halina). Religious beliefs and faith provided a framework offering a sense of meaning:

I’m a better Muslim because of my religion, it really explains everything about how to overcome challenges, how to become a good mother ... There’s so many things you can learn from my religion. It’s the main factor that I can accept it because of my religion ... Because we have the Qur’an ... you can read it, it explains everything. If God sent you this challenge, means that you are the chosen one. And you should accept it and there will be more good things to come. So you should not worry, just leave it to God and as soon as I did that I think I’m

more calm. I also have a best friend, she helps explain the Qur'an, the Hadith, what should you do if you were given these kind of challenges. That's why I can deal with it. I think I can overcome the denial stage quite fast compared to some of the other parents. (Amina)

Several aspects of their religious practices that were frequently mentioned as helpful included praying, reading the Qur'an, and going to church. Both internal and external spiritual supports were identified:

Most important is my religion, when we have our Rosary moments and all that every month. We see our church people and they will motivate us. Those people actually, it helps to strengthen me. Praying, going to church ... I'm a Catholic ... without faith you're nothing actually. Your beliefs are actually very important ... it's like all a plan, God's plan to have him in our lives.

We support each other: Community support

Despite the general lack of awareness in Malaysia, six mothers described receiving various community supports, mostly from ASD parent support networks or religious institutions. Winnie explained, "We have many parent support groups. Other parents who have been there longer, they would give us advice. We share, we support each other."

ASD in the globalised internet age

All mothers described finding information from resources globally or online, to compensate for the more limited supports received locally. The resources online were mostly positive but also could be overwhelming for mothers with newly diagnosed children:

Then from there onwards, I went and did my own research. I went to the internet, I start reading, I start researching from scratch, from zero, from nothing. I didn't even know how to spell autism. (May Lin)

There's a very good webpage (blog) of a mother with two children with autism. She gives you lots of ideas. (Shirin)

Facebook and online support groups were identified as particularly beneficial. Given time constraints, the mothers found browsing online a convenient, economical source of information that generally helped ease their worries and helped them build a broader sense of community and supportive resources.

Discussion

The present study explored how Malaysian mothers of children with autism made sense and gave meaning to their experiences, adaptation, and wellbeing development. These experiences were found to be strongly influenced by situational, cultural, interpersonal, and

intrapersonal factors. In making sense of their experiences, mothers interpreted autism as a voyage. These findings of following a coping journey are in line with previous writings on the process parents go through grieving, adjusting, and accepting their child with ASD (e.g., Jardine, 2008). Additionally, mothers described worrying about their children's future, perceiving taking care of their child as a non-stop, ongoing process. This interpretation may help to explain why in previous studies, the stress levels of Malaysian parents did not decrease as their child grew older (DeLambo et al., 2011; Jiar & Xi, 2012).

Similar to the poor awareness about ASD previously described in the literature (Neik et al., 2014), many mothers in this study were not familiar with "autism" beforehand. There was a clear need to take into consideration the context that mothers lived in, in order to fully understand their wellbeing (Garrod, 2013; Manderson, 2005). The mothers described being provided with critical causal explanations for the condition, making their journey towards sense-making and wellbeing more challenging initially.

The results support previous findings that ASD affects the entire family system (e.g., Cridland, Jones, Magee, & Caputi, 2014; Morgan, 1988). Despite supportive family members, mothers recounted challenging experiences within their nuclear family and some troubled family functioning. The mothers reported feeling stressed, depressed, and tired, similar to past quantitative studies in Malaysia (e.g., Nikmat et al., 2008) and Singapore (Lai et al., 2015). However, despite these difficulties, the mothers still strove to give their best to their child. They "accepted" the condition and became "empowered," engaged to be "proactive" (Weiss, Cappadocia, MacMullin, Viecili, & Lunskey, 2012).

The mothers' experiences were also similar to the findings from Manning et al.'s (2011) study with regard to the double ABCX model components. For example, the mothers in the present study similarly mentioned the initial stressors they faced as well as the reported accumulation of other stressors postcrisis, such as divorce/widowhood and employment challenges. The mothers faced difficulty taking care of their child with ASD due to certain child characteristics, such as frequent behaviour problems. Hyperactivity (similar to McStay et al., 2014) and sleep issues were especially highlighted by participants, suggesting the importance of future efforts in addressing these behavioural impacts on parental wellbeing. The mothers in the present study also described the benefits of parental support groups, and positive thinking (Hastings, Kovshoff, Ward, et al., 2005). Furthermore, parental perceptions and the positive cognitive appraisal of the condition and stressors played a key role.

Similar to Lai et al.'s (2015) findings of culture-specific coping behaviour, the present study illustrated the impact of cultural lay beliefs on the mothers' wellbeing and conceptualisations of disability. For example, all mothers with a Chinese background were told by their extended families that they might have a child with autism because of the traditional Chinese belief of "past lives" or the wrongdoing of the ancestors. Treatments and diagnostic resources in the country were described as limited and expensive (Ting & Chuah, 2010; Toran, 2011), and these situational factors added to the burdens experienced by the mothers. Therapies provided by the government hospitals had long waiting lists, forcing the mothers to seek treatments in the private sector or turn to alternative treatments. All mothers in the study seemed to be financially burdened, similar to previous findings (e.g., Jiar & Xi, 2012; Swanepoel, 2003).

The present study supported a multidimensional understanding of wellbeing, and its conceptualisation as more than just the absence of depression and poor mental health. Stressors and sadness were intermingled with joy and flourishing, supporting an understanding of wellbeing similar to the construct of resilience, rising above and thriving in the face of adversity.

The findings also suggested that Seligman's (2011) PERMA framework has applicability towards understanding the wellbeing of parents of children with ASD. In Seligman's PERMA model, positive emotions referred to hedonic feelings of joy and happiness as well as the emotions experienced by the participants, such as contentment, comfort, and acceptance. Engagement referred to finding a sense of flow, absorption, and psychological connection to activities in life (Seligman, 2011). All the mothers emphasised that their initiative and engagement in their child's treatment fostered wellbeing. Positive relationships referred to feeling socially integrated, cared about and supported by others, and satisfied with one's social connections. Although family quarrels and challenges occurred and the broader society/government support was lacking, the women were able to find ways to tap into relationships with their own children, spouses, extended family, and especially other parents of children with ASD. They believed that equipping themselves with knowledge would be the solution, employing a proactive, solution-focused coping strategy. Online relationships and supports were uniquely mentioned and could be further explored to expand upon the recent findings of Roffeei, Abdullah, and Basar (2015) regarding the support offered by Facebook groups in Malaysia.

In PERMA (Seligman, 2011), meaning referred to believing that one's life is valuable and feeling connected to something greater than oneself. The mothers all spoke

of finding meaning and a sense of purpose through their role as a mother to a child with autism and they linked this personal growth perspective with better wellbeing. The meaningfulness of the experience was associated with a character development process (e.g., developing patience). They moved towards acceptance, tapped into spiritual supports, and used reframing to find meaning. Participants from different religious identifications, and those identifying as "free thinkers," pointed to the support offered by spirituality to their meaning-making process. Furthermore, they desired to contribute back to the broader community, raising awareness about ASD, and correcting misunderstandings.

Lastly, accomplishments referred to making progress toward goals, feeling capable of completing activities, and having a sense of achievement and competence (Seligman, 2011). The mothers directly expressed feeling contentment and happiness from their child's accomplishments. Their sense of competence in their ability to guide their children provided them a sense of meaning and purpose. They developed a sense of mastery in their roles as "mothers" and "teachers" to their children (Tsai, Tsai, & Shyu, 2008). The present study's findings complement and build upon McDonnell and Gayson's (2014) description of the relevance of PERMA for fostering happiness and wellbeing in those with ASD and Garrod's (2013) description of PERMA for those with intellectual disability. This present study contributed to the literature by illustrating the relevance of PERMA to understanding parental wellbeing in parents of children with ASD.

Examining these mothers' journeys in context, their wellbeing development can be interpreted as a dynamic process. Both intrapersonal and interpersonal processes were important. Faced with limited interpersonal, external supports, the women tapped into various intrapersonal, internal coping strategies, which helped empower them and motivated a proactive, solution-oriented approach. In our globalised, internet-age world, they identified a network of peers/experts that provided support, similar to Fleischmann (2005). Living in a collectivistic culture, the importance of interpersonal support seemed even more relevant to them (Kağitçibaşı, 2007; Park, 2015). Although the meaning participants found in their experiences were similar to each other, the strength of the IPA design also illuminated that every mother experienced a somewhat different path with unique challenges and supports.

Clinical implications

This study's findings can be used to shape clinical interventions and guide future translational research to construct more dynamic theories of wellbeing and wellbeing

promotion programs, which include contextual components. Seligman (2011) emphasised that the wellbeing components of PERMA are buildable and efforts to translate insights into practice are recommended. A family-centred assessment and treatment approach are recommended. Insights from participants recommended greater paternal involvement during the diagnostic process and development of support groups/systems for fathers and other family members. Guidance provided should be pertinent to the family's cultural background. Professionals should also explore family and spiritual coping resources. Recommendations for both urban and rural regions include improved education facilities, teacher training, and inclusive education settings/opportunities; greater financial support; and more one-stop, interdisciplinary assessment and treatment centres.

Limitations and suggestions for future research

This exploratory study had some limitations that are recommended to be addressed in future research. Eight participants served as a typical IPA sample size, yet an expanded sample in terms of number and diversity is recommended. Moreover, there was the possibility that the mothers who volunteered for the study, compared to those who did not, may have had a greater sense of initiative and wellbeing; thus, further efforts to identify parents struggling as well as those thriving is suggested.

Findings from the current study provided guidance for the broader study's design as well. The methodology of using IPA in the first phase of a larger mixed-methods grounded theory project provided numerous insights. For example, findings led to changes in the interview guides (e.g., questions were added to ask about perceptions of the cause of the condition, family relationships and family wellbeing, as well as past treatments and needs). Furthermore, participants were expanded to include fathers (for qualitative interviews and quantitative survey completion) and to include interviews of professionals to improve triangulation of the data. The research team was expanded to include multidisciplinary researchers (e.g., in the special education field) in recognition of the perspectives offered from diverse professionals and the frequent parental concerns regarding schooling. Additionally, the participants' identification of behaviour, sleep, and family functioning difficulties as challenges informed selection of additional, specific quantitative measures for the broader project.

In future research, examination of sociodemographic factors shaping family experiences is recommended to be studied more closely (e.g., Hidalgo, McIntyre, & McWhirter, 2015), with care to follow the highest ethical principles, especially in developing and low-to-middle

income countries (e.g., Daley et al., 2013). Future research is suggested to consider the dynamic impact of intrapersonal and interpersonal processes and the differing roles these supports may play in more traditional and developing countries. Researchers are also recommended to study fathers, siblings, and extended family members of children with ASD in Malaysia and developing countries to understand their experiences systemically and to develop better interventions to support overall *family wellbeing*. In conclusion, mixed-methods longitudinal studies, exploring challenges and protective processes, are recommended to illustrate the lived experiences of families and individuals with ASD in underresearched regions.

Acknowledgements

We would like to thank the organisations that posted the study flyer and the families who participated in this research.

Funding

The authors would like to acknowledge that this work was supported by the Ministry of Higher Education Malaysia under a Fundamental Research Grant Scheme [FRGS/1/2013/SKK10/MUSM/02/1] and by the Faculty of Medicine, Nursing and Health Sciences, Monash University Australia, under a Faculty Strategic Grant Scheme [SPG066]. There are no restrictions on free access to or publication of the research data.

Disclosure statement

No potential conflict of interest was reported by the authors.

ORCID

Kim Cornish  <http://orcid.org/0000-0003-2014-0193>

Miriam Sang-Ah Park  <http://orcid.org/0000-0002-1269-6856>

Karen Jennifer Golden  <http://orcid.org/0000-0002-1111-3233>

References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Baxter, A. J., Brugha, T. S., Erskine, H. E., Scheurer, R. W., Vos, T., & Scott, J. G. (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine*, 45, 601–613. doi:10.1017/S003329171400172X
- Bayat, M., & Schuntermann, P. (2013). Enhancing resilience in families of children with autism spectrum disorder. In D. S.

- Becvar (Ed.), *Handbook of family resilience* (pp. 409–424). New York, NY: Springer. doi:10.1007/978-1-4614-3917-2_23
- Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012). Effects on resilience of caregivers of persons with autism spectrum disorder: The role of positive cognitions. *Journal of the American Psychiatric Nurses Association, 18*, 337–344. doi:10.1177/1078390312467056
- Biggerstaff, D., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology, 5*, 214–224. doi:10.1080/14780880802314304
- Braunstein, V. L., Peniston, N., Perelman, A., & Cassano, M. C. (2013). The inclusion of fathers in investigations of autistic spectrum disorders. *Research in Autism Spectrum Disorders, 7*, 858–865. doi:10.1016/j.rasd.2013.03.005
- Clark, M., Brown, R., & Karrapaya, R. (2012). An initial look at the quality of life of Malaysian families that include children with disabilities. *Journal of Intellectual Disability Research, 56*, 45–60. doi:10.1111/j.1365-2788.2011.01408.x
- Cornish, K., & Wilding, J. (2010). *Attention, genes, and developmental disorders*. New York, NY: Oxford University Press. doi:10.1093/acprof:oso/9780195179941.001.0001
- Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2014). Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence. *Journal of Autism and Developmental Disorders, 44*, 1261–1274. doi:10.1007/s10803-013-1985-6
- Cridland, E. K., Jones, S. C., Magee, C. A., & Caputi, P. (2014). Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. *Autism, 18*, 213–222. doi:10.1177/1362361312472261
- Daley, T. C. (2002). The need for cross-cultural research on the pervasive developmental disorders. *Transcultural Psychiatry, 39*, 531–550. doi:10.1177/136346150203900409
- Daley, T. C., Singhal, N., & Krishnamurthy, V. (2013). Ethical considerations in conducting research on autism spectrum disorders in low and middle income countries. *Journal of Autism and Developmental Disorders, 43*, 2002–2014. doi:10.1007/s10803-012-1750-2
- Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders, 38*, 1278–1291. doi:10.1007/s10803-007-0512-z
- Davis, T. N., O'Reilly, M., Kang, S., Lang, R., Rispoli, M., Sigafos, J., ... & Mulloy, A. (2013). Chelation treatment for autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders, 7*, 49–55. doi:10.1016/j.rasd.2012.06.005
- DeLambo, D., Chung, W., & Huang, W. (2011). Stress and age: A comparison of Asian American and non-Asian American parents of children with developmental disabilities. *Journal of Developmental and Physical Disabilities, 23*, 129–141. doi:10.1007/s10882-010-9211-3
- Department of Statistics Malaysia (Jabatan Perangkaan Malaysia). (2014). *Findings of the Household Income Survey (HIS) 2013*. Putrajaya, Malaysia: Author.
- Dodge, R., Daly, A. P., Huyton, J., & Sanders, L. D. (2012). The challenge of defining wellbeing. *International Journal of Wellbeing, 2*, 222–235. doi:10.5502/ijw.v2i3
- Dyches, T. T., Wilder, L. K., Sudweeks, R. R., Obiakor, F. E., & Algozzine, B. (2004). Multicultural issues in autism. *Journal of Autism and Developmental Disorders, 34*, 211–222. doi:10.1023/B:JADD.0000022611.80478.73
- Ereaut, G., & Whiting, R. (2008). *What do we mean by 'well-being'? And why might it matter?* (Research Report No. DCSF-RW073). London, UK: Department for Children, Schools and Families.
- Firth, I., & Dryer, R. (2013). The predictors of distress in parents of children with autism spectrum disorder. *Journal of Intellectual & Developmental Disability, 38*, 163–171. doi:10.3109/13668250.2013.773964
- Fleischmann, A. (2005). The hero's story and autism: Grounded theory study of websites for parents of children with autism. *Autism, 9*, 299–316. doi:10.1177/1362361305054410
- Freeth, M., Milne, E., Sheppard, E., & Ramachandran, R. (2014). Autism across cultures: Perspectives from non-western cultures and implications for research. In F. R. Volkmar, S. J. Rogers, R. Paul, & K. A. Pelphrey (Eds.), *Handbook of autism and pervasive developmental disorders* (4th ed., Vol. 2., pp. 997–1013). Hoboken, NJ: Wiley. doi:10.1002/9781118911389.hautc43
- Gardiner, E., & Iarocci, G. (2012). Unhappy (and happy) in their own way: A developmental psychopathology perspective on quality of life for families living with developmental disability with and without autism. *Research in Developmental Disabilities, 33*, 2177–2192. doi:10.1016/j.ridd.2012.06.014
- Garrod, C. J. (2013). *Subjective wellbeing in people with intellectual disabilities* (Unpublished doctoral thesis). University of Hull, Kingston upon Hull, England. Retrieved from <https://hydra.hull.ac.uk/resources/hull:8430>
- Golden, K. J., & Liaw, J. H. J. (2015). Understanding neurodevelopmental disorders in context: Autism spectrum disorder in the family system. In S. Haque & E. Sheppard (Eds.), *Culture and cognition: A collection of critical essays* (pp. 83–108). Bern, Switzerland: Lang.
- Griffith, G. M., Totsika, V., Nash, S., Jones, R. S. P., & Hastings, R. P. (2012). "We are all there silently coping." The hidden experiences of parents of adults with Asperger syndrome. *Journal of Intellectual & Developmental Disability, 37*, 237–247. doi:10.3109/13668250.2012.701729
- Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., degli Espinosa, F., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism, 9*, 377–391. doi:10.1177/1362361305056078
- Hastings, R. P., Kovshoff, H., Ward, N. J., degli Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders, 35*, 635–644. doi:10.1007/s10803-005-0007-8
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*, 629–642. doi:10.1007/s10803-012-1604-y
- Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family

- functioning. *Journal of Intellectual Disability Research*, 50, 874–882. doi:10.1111/j.1365-2788.2006.00904.x
- Hidalgo, N. J., McIntyre, L. E., & McWhirter, E. H. (2015). Sociodemographic differences in parental satisfaction with an autism spectrum disorder diagnosis. *Journal of Intellectual & Developmental Disability*, 40, 147–155. doi:10.3109/13668250.2014.994171
- Hill, R. (1958). Generic features of families under stress. *Social Casework*, 49, 139–150.
- Ilias, K., Ponnusamy, S., & Normah, C. D. (2008, June). *Parental stress in parents of special children: The effectiveness of psychoeducation program on parents' psychosocial well beings*. Paper presented at the Simposium Sains Kesehatan Kebangsaan ke 7 [7th National Health Symposium], Kuala Lumpur.
- Jardine, K. M. (2008). *What meaning does raising a child with autism have for parents? A qualitative exploration* (Unpublished doctoral dissertation). University of Edinburgh, England.
- Jiar, Y. K., & Xi, L. (2012). Parenting stress and psychological distress among mothers of children with autism in Johor Bahru and Hangzhou. *Journal of Educational Psychology & Counseling*, 6, 129–153. Retrieved from <http://core.ac.uk/download/pdf/11799915.pdf>
- Kağıtçıbaşı, C. (2007). *Family, self, and human development across cultures: Theory and applications* (2nd ed.). Mahwah, NJ: Erlbaum.
- Kwok, S., & Wong, D. (2000). Mental health of parents with young children in Hong Kong: The roles of parenting stress and parenting self-efficacy. *Child & Family Social Work*, 5, 57–65. doi:10.1046/j.1365-2206.2000.00138.x
- Lai, W. W., Goh, T. J., Oei, T. P. S., & Sung, M. (2015). Coping and well-being in parents of children with autism spectrum disorders (ASD). *Journal of Autism and Developmental Disorders*, 45, 2582–2593. doi:10.1007/s10803-015-2430-9
- Lai, W. W., & Oei, T. P. S. (2014). Coping in parents and caregivers of children with autism spectrum disorders (ASD): A review. *Review Journal of Autism and Developmental Disorders*, 1, 207–224. doi:10.1007/s40489-014-0021-x
- Manderson, L. (2005). The social context of wellbeing. In L. Manderson & R. Nile (Eds.), *Rethinking wellbeing* (pp. 1–25). Perth, Australia: API Network.
- Manning, M. M., Wainwright, L., & Bennett, J. (2011). The double ABCX model of adaptation in racially diverse families with a school-age child with autism. *Journal of Autism and Developmental Disorders*, 41, 320–331. doi:10.1007/s10803-010-1056-1
- Mannion, A., Brahm, M., & Leader, G. (2014). Comorbid psychopathology in autism spectrum disorder. *Review Journal of Autism and Developmental Disorders*, 1, 124–134. doi:10.1007/s40489-014-0012-y
- Mannion, A., & Leader, G. (2014). Sleep problems in autism spectrum disorder: A literature review. *Review Journal of Autism and Developmental Disorders*, 1, 101–109. doi:10.1007/s40489-013-0009-y
- McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: The double ABCX model of family adjustment and adaptation. *Marriage & Family Review*, 6, 7–37. doi:10.1300/J002v06n01_02
- McDonnell, A. & Gayson, C. (2014). A positive wellbeing approach to behaviours of concern: Applying the PERMA Model. In G. Jones & E. Hurley (Eds.), *Good autism practice: Autism, happiness, and wellbeing* (pp. 18–24). Birmingham, England: British Institute of Learning Disabilities.
- McNulty, J. K., & Fincham, F. D. (2012). Beyond positive psychology? Toward a contextual view of psychological processes and well-being. *American Psychologist*, 67, 101–110. doi:10.1037/a0024572
- McStay, R. L., Dissanayake, C., Scheeren, A., Koot, H. M., & Begeer, S. (2014). Parenting stress and autism: The role of age, autism severity, quality of life and problem behaviour of children and adolescents with autism. *Autism*, 18, 502–510. doi:10.1177/1362361313485163
- Ministry of Health Malaysia. (2011). *Country health plan: 10th Malaysia plan 2011–2015*. Retrieved from http://www.moh.gov.my/images/gallery/Report/Country_health.pdf
- Morgan, S. B. (1988). The autistic child and family functioning: A developmental-family systems perspective. *Journal of Autism and Developmental Disorders*, 18, 263–280. doi:10.1007/BF02211952
- Neik, T. T. X., Lee, L. W., Low, H. M., Chia, N. K. H., & Chua, A. C. K. (2014). Prevalence, diagnosis, treatment and research on autism spectrum disorders (ASD) in Singapore and Malaysia. *International Journal of Special Education*, 29, 82–92. Retrieved from <http://files.eric.ed.gov/fulltext/EJ1045960.pdf>
- Nikmat, A. W., Ahmad, M., Oon, N. L., & Razali, S. (2008). Stress and psychological wellbeing among parents of children with autism spectrum disorder. *ASEAN Journal of Psychiatry*, 9, 65–72. Retrieved from <http://www.aseanjournalofpsychiatry.org/index.php/aseanjournalofpsychiatry/article/viewFile/46/37>
- Norbury, C. F., & Sparks, A. (2013). Difference or disorder? Cultural issues in understanding neurodevelopmental disorders. *Developmental Psychology*, 49, 45–58. doi:10.1037/a0027446
- Park, M. S. (2015). Changing family perceptions across cultures: The Malaysian context. In S. Haque & E. Sheppard (Eds.), *Culture and cognition: A collection of critical essays* (pp. 197–210). London, England: Peter Lang.
- Phelps, K. W., Hodgson, J. L., McCammon, S. L., & Lamson, A. L. (2009). Caring for an individual with autism disorder: A qualitative analysis. *Journal of Intellectual & Developmental Disability*, 34, 27–35. doi:10.1080/136682508.02690930
- Pozo, P., Sarriá, E. & Brioso, A. (2014). Family quality of life and psychological well-being in parents of children with autism spectrum disorders: A double ABCX model. *Journal of Intellectual Disability Research*, 58, 442–458. doi:10.1111/jir.12042
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 8, 20–23.
- Roffeei, S. H. M., Abdullah, N., & Basar, S. K. R. (2015). Seeking social support on Facebook for children with autism spectrum disorders (ASDs). *International Journal of Medical Informatics*, 84, 375–385. doi:10.1016/j.ijmedinf.2015.01.015
- Ruhaizad, D. (2013). Mount Kinabalu climbing information, tips & guidelines [Blog post]. Retrieved from <http://www.mount-kinabalu-borneo.com/mount-kinabalu-history.html>
- Seligman, M. E. P. (2011). *Flourish: A visionary new understanding of happiness and well-being*. New York, NY: Free Press.

- Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist*, 55, 5–14. doi:10.1037//0003-066X.55.1.5
- Smith, J. A. (2003). Shifting identities: The negotiation of meanings between texts and between persons. In L. Finlay & B. Gough (Eds.), *Reflexivity: A practical guide for researchers in health and social sciences* (pp. 176–186). Oxford, England: Blackwell. doi:10.1002/9780470776094.ch13
- Smith, J. A., & Eatough, V. (2007). Interpretative phenomenological analysis. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative data in psychology* (pp. 35–50). London, UK: Sage. doi:10.4135/9781446207536.d10
- Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51–80). London, UK: Sage.
- Swanepoel, Y. (2003). *Primary caregivers' experiences of raising children with autism: A phenomenological perspective* (Unpublished master's thesis). Rhodes University, Grahamstown, South Africa.
- Ting, S., & Chuah, H. (2010). Parents' recognition of autistic behaviour and their coping strategies: A case study of Sarawak autistic association. *International Journal of Social Policy and Society*, 7, 52–65.
- Tint, A., & Weiss, J. A. (2016). Family wellbeing of individuals with autism spectrum disorder: A scoping review. *Autism*, 20, 262–275. doi:10.1177/1362361315580442
- Toran, H. (2011). Experience and challenges in setting up a model demonstration classroom for children with autism in Malaysia. *International Journal of Educational Administration and Development*, 2, 37–47.
- Tsai, W.-C., Tsai, J.-L., & Shyu, Y.-I. L. (2008). Integrating the nurturer–trainer roles: Parental and behavior/symptom management processes for mothers of children with autism. *Social Science & Medicine*, 67, 1798–1806. doi:10.1016/j.socscimed.2008.07.015
- Weiss, J. A., Cappadocia, M. C., MacMullin, J. A., Vecili, M., & Lunskey, Y. (2012). The impact of child problem behaviors of children with ASD on parent mental health: The mediating role of acceptance and empowerment. *Autism*, 16, 261–274. doi:10.1177/1362361311422708