

THE VALUE OF MIXED-METHOD RESEARCH WITH FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER: A GROUNDED THEORY PROTOCOL

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Abstract

This study emphasizes the value of mixed-method research methodologies in research with families of children with Neurodevelopmental Disorders (NDD), specifically Autism Spectrum Disorder (ASD). The category of NDD in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5) includes Intellectual Developmental Disorders, Communication Disorders, Autism Spectrum Disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD), Specific Learning Disorder, and Motor Disorders. NDD affect not only the child, but the family as well. Limited research has utilized a qualitative or a mixed-methods approach to explore the experiences, stressors, and resilience of parents of children with ASD in non-Western contexts. Providing an example of a mixed-methods design, this paper illustrates a multiple-phase doctoral study on Autism Spectrum Disorder (ASD). The study's objective is to conduct an embedded design, mixed-method analysis using grounded theory to better understand parents' (mothers and fathers) experiences, stressors, well-being and resilience in the Malaysian cultural context. Integrating and blending the approaches together allows for deeper analysis and theory development, while allowing rich cultural data to be shared in research areas where limited information is present. Revealing the family system, cultural, and contextual processes, the findings have important implications for professionals and researchers to develop more meaningful, culturally-tailored, and evidenced-based interventions.

Keywords: Autism Spectrum Disorder (ASD), Neurodevelopmental disorders, mixed-method research, Asia, clinical psychology, embedded design, qualitative, autism, culture, Malaysia

Abstrak

Kajian ini menerangkan metodologi penggunaan kaedah bercampur dalam penyelidikan mengenai keluarga yang mempunyai anak yang mengalami Kecelaruhan Perkembangan Saraf dan Perilaku (NDD), khususnya Kecelaruhan Spektrum Autisme (ASD). Berdasarkan manual diagnostik dan statistik kecelaruhan edisi kelima (DSM-5), kategori NDD merangkumi ASD, kecelaruhan perkembangan intelek, kecelaruhan komunikasi, kecelaruhan hiperaktif dan kurang tumpuan (ADHD), kecelaruhan pembelajaran spesifik, dan kecelaruhan motor. NDD bukan hanya memberi kesan kepada kanak-kanak, tetapi juga kepada ahli keluarganya. Kajian kualitatif yang menggunakan pendekatan kaedah bercampur ke atas pengalaman, tekanan, dan daya tahan ibubapa yang mempunyai anak ASD adalah terhad di negara bukan barat. Kajian ini merupakan satu contoh rekabentuk penyelidikan menggunakan kaedah bercampur dalam pelbagai fasa pengajian di peringkat kedoktoran (PhD) terhadap keluarga anak-anak yang mempunyai ASD. Objektif kajian ini adalah untuk memahami pengalaman, tekanan, kesejahteraan dan daya tahan ibu bapa yang mempunyai anak ASD dalam konteks budaya Malaysia dengan menggunakan pendekatan kaedah bercampur berdasarkan teori. Dengan mengintegrasikan dan mengadakan pendekatan kaedah bercampur, analisis dan pembentukan teori yang lebih mendalam mampu dihasilkan, disamping membuka ruang untuk perkongsian maklumat berkaitan budaya yang masih terhad pada masa kini. Pendedahan mengenai sistem kekeluargaan, budaya dan proses kontekstual, hasil kajian ini mampu menjadi rujukan kepada ahli

profesional dan penyelidik dalam menghasilkan kaedah intervensi yang bersesuaian dengan budaya dan juga berasaskan bukti.

Kata Kunci: Kecelaruhan Spektrum Autisme (ASD), Kecelaruhan Perkembangan Saraf dan Perilaku (NDD), penyelidikan menggunakan kaedah bercampur, Asia, Psikologi Klinikal embedded design, kualitatif, autisme, budaya, Malaysia

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1.0 INTRODUCTION

Approximately 12% of children aged 3 to 17 years have Neurodevelopmental Disorders (NDD) [1]. In [2], the category of NDD includes Intellectual Developmental Disorders, Communication Disorders, Autism Spectrum Disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD), Specific Learning Disorder, and Motor Disorders [2]. Moreover, when studying NDD, comorbidity is commonly found [2].

The prevalence of ASD has been reportedly increasing worldwide, with reported frequencies for ASD in the United States and outside the United States approaching 1% of the population [2, 3]. ASD is a lifelong neurodevelopmental disorder that affects not only the child, but also the entire family system as a unit [4]. ASD is characterized by symptoms and difficulties in social communication and social interaction across multiple contexts, and a tendency to engage in restricted, repetitive patterns of behaviours, interests, or activities [2]. Moreover, ASD is often co-morbid with symptoms of other medical and psychological disorders [2], such as attention-deficit/hyperactivity disorder (ADHD) [5, 6], obsessive-compulsive disorder [7], depression [8], and sleep disorders [9]. These comorbid symptoms as well as the primary symptoms of ASD can significantly affect the quality of life of individuals with an ASD and their families [10].

Parenting in general can be stressful, regardless of place of residence, but parenting children with ASD can be even more stressful and burdensome, especially in countries where support resources are scarce. There is little question that raising a child with an ASD constitutes a significant stressors for parents. Across the literature, parents of children with an ASD frequently report higher levels of depression [11], higher levels of anxiety [4], and more health related problems [12]. Existing research regarding adaptation of parents of children with ASD has shown elevated stress levels for both mothers and fathers [13]. Parents of children with autism have been found to have higher levels of stress and depression and lower level of wellbeing than parents of typically developing children [14,15], and children with other developmental disabilities such as Down syndrome [16].

This paper illustrates a multi-phase doctoral study examining a NDD, specifically Autism Spectrum Disorder (ASD) in the Malaysian context. Malaysia has

a unique ethnically and religiously diverse population [17]. Although differing ethnic and religious values as well as family traditions may differently affect parental perceptions, stress and coping, these factors have been underexplored. Also, research has suggested the experience of mothers and fathers differ in important ways; however, problematically, fathers have often been underrepresented in studies of families of children with NDD [18].

Thus, the current study seeks to address the lack of research to date exploring the experiences, including the risks and protective processes, which contribute to parental stress and resilience for parents of children with ASD in the Malaysian setting. A body of research exists exploring parenting children with Autism Spectrum Disorder (ASDs) and the impact on the parents and families quantitatively. However, there are fewer studies that have explored qualitatively the experiences, parenting stress, and resilience of the parents. Mixed-methods studies, studies using both quantitative and qualitative methods in combination, are even less common. The rationale of combining the quantitative and qualitative approaches in the present study is that the two approaches complement each other and allow for a deeper analysis and development of a culturally-relevant theory, while allowing rich cultural data to be shared in this area where very limited information is present [19, 20].

2.0 LITERATURE REVIEW

Autism Spectrum Disorder (ASD) is a NDD defined in the DSM-5 by deficits in two behavioral domains: social communication and social interaction; and restricted repetitive behaviors, interests and activities (RBBs) [2]. These symptoms become apparent in the early developmental period and are pervasive in nature, usually affecting individuals throughout their lifespan [2, 21]. Growing research evidence suggests the strong etiological role of genetic and neurobiological factors [2]. The reported prevalence of ASD has been increasing worldwide [22] with an estimated 52 million persons identified as having ASD [3]. Likewise, in Malaysia, doctors, psychologists, and psychiatrists have reported an increase in the number of children with ASD in their clinics and classes [23], illustrating the urgency of the need for more research in this growing problem area. Few studies have researched ASD in Malaysia [15, 23, 24]. Kee, Yeo & Lu Xi found that the difficulty learning to

speak was the first symptom reported by Malaysian mothers [24].

Having a child with ASD in the family system has more often been associated with negative rather than with positive experiences in past studies [11]. The presence of a child or children with ASD in the family may have adverse effects on various domains of parental relations and family life. These influences may include strained marital and sibling relationships, impacting family socialization and family routines as a whole [25]. A child with ASD in the family creates a situation that requires understanding of the eco-systemic context, including the extended family, friends, and the community and professional caregivers [26].

Common sources of stress in parents of children with ASD include the child's inappropriate and unpredictable behaviors and emotional problems, financial worries secondary to needs to obtain specialized intervention and educational services, as well as concerns about the future of their children [27, 28]. Behavioral and emotional problems often occur at higher rates in individuals with ASD and the rate of such problems has been shown to contribute to the stress of parents of children with ASD, especially maternal stress [29]. Mothers of children with ASD have often been found to play the role of the primary caregiver [18]. The behavior repertoire of the individuals with ASD has been shown to have an impact on members of both the immediate and the extended family system [30]. Contextual factors predictive of stress have been examined less frequently, but they may be important factors to consider, especially in cultures with more collectivistic traditions [31].

Researchers have described that qualitative and quantitative research strategies differ in their contrasting epistemological and ontological assumptions [32]. However, Bryman asserted that qualitative and quantitative methodologies should not be viewed as incompatible, rather they can be combined [33]. Mixed-methods research has been recommended when this approach best answers the given research questions [33]. There has been growing recognition of the value of a mixed-method design [34]; however, problematically, most researchers have faced barriers fully *integrating* the approaches together [35].

The use of metaphors can facilitate understanding the mixed-method design process [36]. The *blending approach* is a useful metaphor to understand the rationale behind using the mixed-method design, such as blending or melding the different sounds to create a symphony [36]. The blending approach offers more information from different sources merged together in symphony to construct insightful understanding and analysis. In investigating the families of children with ASD, the mixed-method design suits the nature of the research into understanding NDD, which involves the complex and dynamic processes the family members experienced [37]. The mixed-method design offers in-depth

analysis and provides meaningful and rich clinical implications for healthcare and educational professionals to develop culturally tailored and evidence-based interventions.

3.0 METHODOLOGY

A mixed-method, grounded theory approach will be utilized, similar to Charmaz's social constructivist perspective, which "emphasizes diverse local worlds, multiple realities and the complexities of particular worlds, views and actions" [38] and also recognizes that "the 'discovered' reality arises from the interactive process and its temporal, cultural, and structural contexts" [39]. Charmaz views grounded theory methods "as a set of principles and practices, not as prescriptions or packages" [40] and emphasizes "flexible guidelines, not methodological rules, recipes and requirements" [40]. The constructive grounded theory approach assumes that data and theories are neither emergent nor discovered but rather are *constructed* by both the researcher and the research participant [40, 41, 42].

3.1 Research and Sampling Design

Previous study in [42] had described that the mixed-method sampling process involves seven distinct steps as follows: (a) determine the goal of the study, (b) formulate the research objective(s), (c) determine the research purpose, (d) determine the research question(s), (e) select the research design, (f) select the sampling design, and (g) select the individual sampling schemes. In the embedded mixed-methods design, one data set provides a supportive, secondary role in a study based primarily on the other data set [43].

In this study protocol, the quantitative data will serve the supportive, secondary role to the qualitative data set. A secondary purpose of the quantitative dataset will be to identify predictors that contribute to parental stress using a set of questionnaires, including the Parenting Stress Index-Short Form (PSI-SF); Depression, Anxiety and Stress Scale (DASS); Family Assessment Device, General Functioning Subscale (FAD-GF); Developmental Behavior Checklist-Parent (DBC-P); the Social Responsive Scale-2 (SRS-2); and the Pittsburgh Sleep Quality Index (PSQI), with the parents of children with ASD and parents of children with typical development in Malaysia. Also, group comparisons between these two parent groups will be conducted. It is hypothesized that the scores of the parents of children with ASD group will be higher than the scores of the parents of children with typical development group on the PSI-SF, DASS depression subscale, FAD-GF, DBC-P, SRS-2, and PSQI. Also, it is hypothesized that the DASS depression subscale, FAD-GF, DBC-P, SRS-2, and PSQI will predict the dependant variable (parenting stress, PSI-SF scores) in the multiple regression analysis. Child age and child

gender may be considered as well (to serve as controls).

The reasons for collecting the secondary dataset (the quantitative dataset) are to address different, but related, questions and to provide support for the primary research purpose. It is important to have a clear and deliberate relationship between the methods in order to ensure that research findings can be systematically integrated and triangulated together to generate more profound insights than a single research method alone.

The first exploratory phase of this doctoral study involved semi-structured qualitative interviews with mothers of children with ASD. The reason for conducting these pilot exploratory interviews was to gain insight into the area and to guide for the main qualitative phase and the quantitative phase. The Interpretive Phenomenological Analysis (IPA) approach was utilized in the exploratory pilot phase with a sample of eight mothers of children with autism. Figure 1 illustrates the current mixed-methods research design in more detail.

3.2 Sample Size

It is necessary to consider the size of the research sample to minimize potential random error in the sampling process [44]. The ideal sample size for this study has been determined on the basis of several factors, including the research objective(s), research question(s) and subsequently the research design [43]. There are proposed sample sizes for several of the most common research designs.

For example, for qualitative studies, there are guidelines for selecting a sample size based on the research design, sampling design and data collection procedure [43]. Creswell has proposed a minimum of 20-30 participants in the grounded theory research design [38]. On the other hand, a minimum of 12 participants is useful for an interview-based data collection procedure [45].

In general, the sample sizes in qualitative research should not be too small as to make it difficult to achieve data saturation, theoretical saturation, or informational redundancy.

As for the study's quantitative strand, a sample size of 106 participants in each group (50+8(7 IV's) is recommended for this research design. This projection is based on the widely used rule of thumb for determining sample size in multivariate regression ($50 + 8 * \text{the numbers of IVs}$) [47]. However, considering possible missing data and dropout rate, the researchers decided to aim for a total number of 120 participants for the quantitative cycle in each group (120 parents of children with ASD and 120 parents of children with TDC). Recruitment methods were set to match the children in the two groups (typical development and ASD) within a close age range (i.e., 12 months of age). At the same time, the sample should not be so large that is difficult to undertake a deep and in-depth analysis [46]. The proposed 30 to 40 qualitative participants in this study (parents and key informants/professionals) appear within or above the suggested range for grounded theory research.

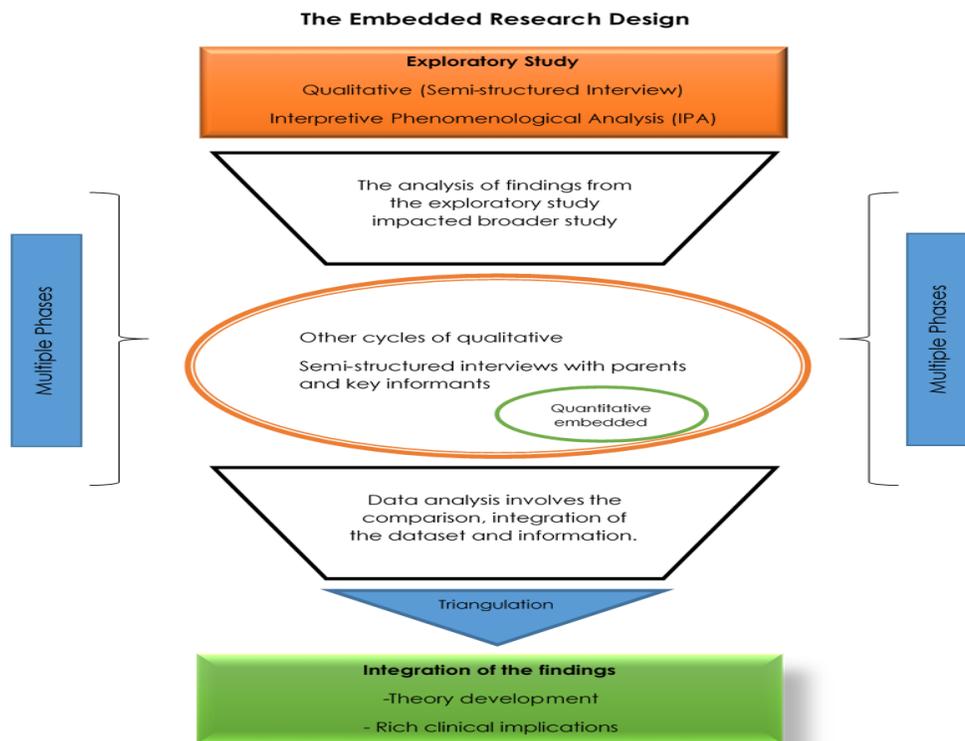


Figure 1 The mixed-method embedded research design

3.3 Participants

Participants were the parents of a child or children with ASD (both mothers and fathers), and the key informants/professionals (selected among health and mental health professionals; staff working in the treatment centres or schools of children with ASD; and members or leaders of current ASD-related support groups). This study uniquely includes fathers along with mothers, as fathers have been understudied in previous research [18]. Furthermore, novel data from those involved in service provision to this population will be gathered to construct a more comprehensive theoretical understanding, integrating more expert understanding of the contextual environment in Malaysia. One hundred and twenty parents of children with ASD and 120 parents of typically developing children were targeted to complete the questionnaires. Approximately 25–30 parents of children with ASD and 5–10 key informants were targeted to be interviewed. An eligibility screening was conducted prior to the selection of the participants.

3.4 Procedure

Following approval from the Monash University Human Research Ethics Committee (MUHREC), flyers for recruitment were posted and distributed in different centres, schools, online parent support groups and non-governmental organizations in Malaysia. Upon initial contact initiated by the potential participant in response to the advertisement, a member of the research team conducted a brief screening interview by telephone or in person with the parent or guardian to determine whether the parent and child meets eligibility criteria. Eligibility criteria include:

- a) Able to read and understand English or Bahasa Malaysia sufficient to be able to complete the consent forms and questionnaire.
- b) Be a parent or guardian of a child with an Autism Spectrum Disorder (aged between 5–13 years for the quantitative phase)
- c) Be a parent or guardian of a typically developing child (aged between 5–13 years for the quantitative phase)

Parents/Guardians will be excluded if:

- a) They are not able to read and understand English or Bahasa Malaysia sufficient to be able to complete the consent forms and questionnaire.
- b) Also, for the parents of children with an Autism Spectrum Disorder, they will be excluded if they report that their child has not been diagnosed previously by a medical or mental health professional with an Autism Spectrum Disorder. Following the initial eligibility screening, parents who fit the eligibility criteria will be contacted further to arrange a meeting or meetings. The Social Responsive Scale-2

(SRS-2) will also be utilized to help substantiate the ASD diagnosis.

The study includes several phases. The grounded theory approach can include both qualitative and quantitative data [48]. Glaser and Strauss in 1967 described that grounded theory is a general method that accepts both qualitative and quantitative data, and claimed that grounded theory is a general method of comparative analysis [48]. Glaser and Strauss explained that the slices of data collected for theoretical sampling are varied, offering researchers with many options for data gathering including different collection techniques, data types and ways of analysing data with the objective of generating different views or vantage points from which to understand a category and to develop its properties theoretically [48].

The survey, face-to-face meetings and interviews with the participants took place at a location of convenience for the participants. Each parent participant was given a RM 30 incentive in the form of a shopping voucher for the completion of the survey. If both parents completed the survey, they were given RM 60 in total. Each parent who participated in the interview was given a RM 50 voucher.

3.5 Instruments and Measurements

Prior to data collection, participants were given an explanatory statement and consent form to read and sign. Parents completed a history and demographic questionnaire including the age of parents; family composition; marital status; religion; ethnicity; parents' highest level of education; household income; presence of household assistant (maid); occupation type; working hours; information about the child's diagnosis, medication use, and co-morbid conditions; information about any medical or psychiatric conditions with the child's siblings; child's attendance at interventions and therapies; child's sleeping location; child's school type; and child's after or before school activities.

For the qualitative strands, an interview guide, including a set of semi-structured open ended questions, and follow up probes guided the process of face to face interviews with the participants. Audio recording was used in the interviews. In addition, handwritten notations were taken as necessary. Key events that were explored in the interviews included: early recognition of the child's symptoms, the diagnosis process, treatment and interventions sought, experiences about parenting, the stressors and challenges faced, successful and unsuccessful coping strategies, cultural influences in the process, family and social support, and future recommendations to other parents, society and government (See Table 1).

The criteria for judging a qualitative study differs from the criteria for judging a quantitative study. In a qualitative design, the researcher seeks believability, based on coherence, insight, and instrumental utility

and trustworthiness through a process of verification rather than through traditional validity and reliability measures [49].

The variables for the quantitative strand were chosen following an extensive literature review of past international and regional studies, while prioritizing instruments with existing validated translations and strong psychometric properties. The findings of the pilot exploratory interviews also informed measure selection (see Figure 1). Measures selected for the study included the following psychometrically-strong inventories: the Parenting

Stress Index (PSI)-Short Form; the Depression, Anxiety and Stress Scale (DASS); the General Functioning Subscale (FAD-GF) of the Family Assessment Device (FAD-GF); the Developmental Behavior Checklist-Parent (DBC-P); the Social Responsive Scale (SRS-2); and the Pittsburgh Sleep Quality Index (PSQI). Table 2 illustrates the summary and description of the reliability for each of these scales.

Table 1 Qualitative interview guide

Interview Guide:
Interview Topics, Questions, and Prompts
<ol style="list-style-type: none"> 1. Please begin by telling me about your experience of having a child with Autism Spectrum Disorder. <ol style="list-style-type: none"> a. Possible prompts regarding the diagnosis if not mentioned. <ol style="list-style-type: none"> i. Tell me about your experiences of first observing something of concern with your child. ii. Tell me about your experience of learning your son/daughter has an Autism Spectrum Disorder. iii. Tell me about the diagnosis process. 2. Based on your experiences of raising a child with autism, what experiences have been most meaningful to you? 3. Tell me about your experience of having a child with autism in your family. <ol style="list-style-type: none"> a. Tell me about how having a child with ASD has affected your family? b. What sort of behaviors affected your family the most? 4. Tell me about the relationships between your child with Autism Spectrum Disorder and his/her siblings, you, your husband, and grandparents? <ol style="list-style-type: none"> a. How was your family affected? 5. Tell me about any stressors or challenges, if any, that you have faced. <ol style="list-style-type: none"> a. Being a parent to a child with autism. b. Having a child with Autism Spectrum Disorder. c. Having a child with Autism Spectrum Disorder in your family. 6. Tell me about what has helped you. <ol style="list-style-type: none"> a. Tell me about what has helped improve your well-being. b. Tell me about what has helped improve your family well-being. c. Tell me about what or who has helped or supported you. d. How have you and your family coped with having a child with Autism Spectrum Disorder? 7. Tell me about the experience of being a parent to a child with Autism Spectrum Disorder in Malaysia and in your culture. 8. Please describe the services, treatment, education that you have sought? 9. What is your understanding of the development of your child condition? 10. If you could provide advice or suggestions to other parents with a child with Autism Spectrum Disorder in Malaysia, what would it be? What advice or suggestions would you give to other parents to help improve their family well-being? What advice or suggestions would you like to give to mental health and health professionals in Malaysia? 11. 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.

Table 2 Description and psychometric properties of the measurements

Measure/ Scale Authors	Description	Psychometric Properties
Parent about Child Survey		
Developmental Behavior Checklist-Parent (DBC-P) (Brereton, Tonge, Mackinnon, Einfeld, 2002)[50]	A 96 item parent-report tool for the assessment of behavioural and emotional disturbance in 4 – 18 year old children. A cut off score of 17 on the subcomponent of the DBC (The Autism Screening Quotient) screens at-risk young people.	$\alpha = .85$ (Giallo et al., 2013) [51]
Social Responsiveness Scale-2 (SRS-2) (Constantino & Gruber, 2012)[52]	A 65-item parent report screening questionnaire for ASD in children. In addition to a Total score reflecting severity of social deficits in the autism spectrum, the SRS-2 generates scores for five Treatment subscales: Social Awareness; Social Cognition; Social Communication; Social Motivation; Restricted Interests and Repetitive Behavior. Responses are scored on an ordinal 4 point Likert scale ranging from 1 (<i>not true</i>) to 4 (<i>almost always true</i>). T scores 60 and above are suggestive of clinically significant ASD symptoms.	$\alpha = .95$ (Constantino & Gruber, 2012)[52]; see also Frazier et al., 2014) [53]
Parent about Parent Survey		
Depression, Anxiety, Stress Scale (DASS-21; Lovibond & Lovibond 1995)[54]	The DASS-21 is a 21-item, self-report questionnaire designed to measure the emotional states of depression, anxiety, and stress in which respondents rate the symptoms of the respective emotional states experienced over the past week on a 4-point Likert scale ranging from 0 (<i>did not apply to me at all</i>) to 4 (<i>applied to me very much or most of the times</i>)	$\alpha = .91$ (Lovibond & Lovibond, 1995) [54]
General Functioning Scale of Family Assessment Device (FAD-GF; Epstein et. al., 1983)[55]	The 12-item GF is a shorter version of the FAD, and provides a rating of overall health and functioning of the family. Each of the 12-items in the GF is measured on a four- point Likert scale ranging from 1 (<i>strongly agree</i>) to 4 (<i>strongly disagree</i>).	$\alpha = .86$ (Byes et.al., 1988)[56]
Parental Stress Index-Short Form (PSI-SF; Abidin,1995)[57]	The PSI-SF includes three subscales: Parental Distress (PD), Parent-child Dysfunctional Interaction (PCDI), and Difficult Child (DC), each containing 12 items. Parents rate each of the 36 items on a five- point scale ranging from 1 (<i>strongly disagree</i>) to 5 (<i>strongly agree</i>).	$\alpha = .80$ to $.87$ for three subscales (Abidin,1995) [57]
Pittsburgh Sleep Quality Index (PSQI) (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989)[58]	A self-report questionnaire pertaining to sleep descriptors of adults occurring over a one-month interval. The sum of 19 items generates 7 subscale scores related to sleep quality, sleep duration, sleep latency, sleep disturbances, sleep medications and daytime dysfunction.	$\alpha = .62 - .72$ (Buysse, et al., 1989)[58]

4.0 DATA ANALYSIS

Qualitative strand: The qualitative data analysis includes a few steps. The first step is to transcribe the interviews. Transcribing involves a close observation of the data collected through listening to the audio recorded interview. Caution and close attention to details should be given to the transcribing process as this is a first interpretative process and crucial step in data analysis [59].

The audio recorded interviews will be transcribed into electronic format. The Malay language interviews will be translated directly into English by the doctoral researcher. Before analysis, the transcripts will be examined by the supervisors to maintain accuracy and quality. Meaningless and redundant utterance like “you know” or “this thing” may be eliminated to aid in the clarification of analysis and increase the readability. Any language added by the transcriber/ researchers that intends to increase the clarity will be placed in brackets. Later, the NVivo 10 software will be used in the organization of the data coding.

The next step is coding. Coding is a process of sorting, organizing, summarizing and synthesising the data. It also serves as the basis of developing in-depth and analytical analysis. The coding process itself involves a few steps. There are some similarities and differences of coding processes in qualitative studies depending on the nature, design and aim of the study. Throughout data analysis and interpretation, coding checks and theme review will be conducted with the supervisors. Final codes and themes will be critically compared with findings from the previous literature.

Quantitative strands: Univariate and multivariate data screening will be conducted prior to the statistical analysis of the quantitative survey results [47]. Data screening will include the descriptive statistics for all the variables, information about missing data, normality, linearity and homoscedasticity, multivariate outliers, multicollinearity and singularity. Descriptive statistics for the survey items will be summarized in the text and reported in tabular form. Later, inferential statistics will be conducted for hypotheses testing and further analysis. Statistical analysis of the quantitative results will be conducted with the help of the IBM Statistical Package for Social Sciences software (SPSS). Figure 2 illustrates the steps of data analysis.

5.0 CONCLUSION

Today's research world is becoming increasingly interdisciplinary, complex, and dynamic [60]. Using multiple research methods enhances concrete and theoretical understandings, facilitates communication, promotes collaboration, and provides a greater research outcome [43]. In regards to this research study, the mixed-method approach

has the potential to enhance in-depth understanding of the contextual and dynamic, ongoing parenting

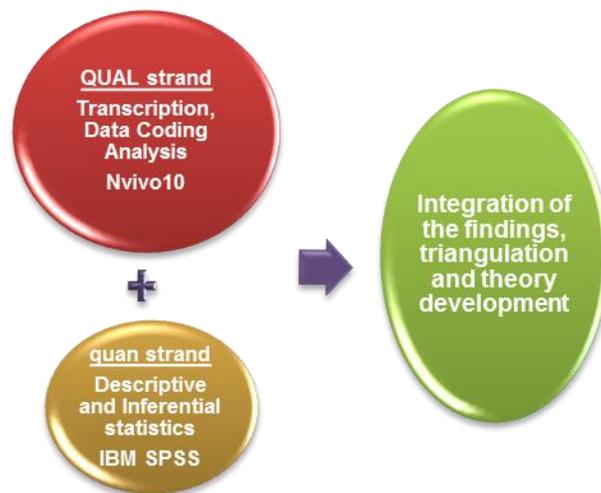


Figure 2 Steps of data analysis

processes and challenges experienced by family members of children with ASD.

This paper provides an example of a mixed-methodology research protocol. An embedded design, multiple phase study protocol was summarized in which the quantitative data will serve the supportive, secondary role to the qualitative data set. The study utilizes a blending approach integrating the data sources together, describing the metaphor of a symphony of sounds. A grounded theory approach similar to Charmaz's social constructivist perspective will be utilized. The study aim is to better understand the experiences, stressors, well-being and resilience of parents' of children with ASD in the Malaysian cultural context. An Interpretive Phenomenological Analysis (IPA) approach is utilized in the exploratory, qualitative pilot phase. In the main study phases, the protocol also uniquely includes recruitment of both mothers and fathers as well as professionals to provide more holistic perspectives. The quantitative component includes a range of psychometrically strong scales to explore the predictors of parenting stress in parents of children with ASD and parents of children with typical development as a comparison group.

Integrating and blending the approaches together in a symphony allows for deeper analysis and theory development, while allowing rich cultural data to be shared in research areas where limited information is present [37]. Greater attention is recommended for research on ASD in developing countries, more rural regions, Aboriginal communities, as well as in marginalized or vulnerable populations. Revealing the family system, culture, and contextual processes can provide rich clinical implications for providing better support before, during and after the

diagnostic process as well as during intervention and treatment. Deepening the knowledge base with mixed-methods findings has important implications for health and educational professionals and for researchers to develop more meaningful, culturally-tailored, and evidenced-based interventions.

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References

- [1] Environmental Protection Agency. 2013. *American Children and the Environment 3rd ed. (ACE3)*. Washington, DC: U.S. Environmental Protection Agency.
- [2] American Psychiatric Association. 2013. *Diagnostic and Statistical Manual of Mental Disorders (5th ed.)*. Arlington, VA: American Psychiatric Publishing.
- [3] Baxter, A. J., Brugha, T. S., Erskine, H. E., Scheurer, R. W., Vos, T. & Scott, J. G. 2014. The Epidemiology and Global Burden of Autism Spectrum Disorders. *Psychological Medicine*. 1–13.
- [4] 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: The International Journal of Research and Practice*. 18(3): 213–22. doi:10.1177/1362361312472261
- [5] Cornish, K., & Wilding, J. 2010. *Attention, Genes, and Developmental Disorders*. New York: Oxford University Press.
- [6] Gargaro, B. A., Rinehart, N. J., Bradshaw, J. L., Tonge, B. J., & Sheppard, D. M. 2011. Autism and ADHD: How Far Have We Come in The Comorbidity Debate? *Neuroscience & Biobehavioral Reviews*. 35(5): 1081-1088. doi: 10.1016/j.neubiorev.2010.11.002
- [7] Ivarsson, T., & Melin, K. 2008. Autism Spectrum Traits in Children and Adolescents with Obsessive-Compulsive Disorder. *Journal of Anxiety Disorders*. 22: 969-978.
- [8] Mandy, W. P., & Skuse, D. H. 2008. Research Review: What Is The Association Between The Social-Communication Element of Autism and Repetitive Interests, Behaviours and Activities? *Journal of Child Psychology and Psychiatry*. 49(8): 795-808.
- [9] Mannion, A., & Leader, G. 2013. Sleep Problems in Autism Spectrum Disorder: A Literature Review. *Review Journal of Autism and Developmental Disorders*. 1(2): 101–109. doi:10.1007/s40489-013-0009-y
- [10] Nazeer, A., & Ghaziuddin, M. 2012. Autism Spectrum Disorders: Clinical Features and Diagnosis. *Pediatr Clin North Am*. 59(1): 19–25.
- [11] 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(3): 629-642.
- [12] Pakenham, K.I., Sofronoff, K., & Samios, C. 2004. Finding Meaning In Parenting Child with Asperger Syndrome. Correlates of Sense Making and Benefit Finding. *Research in Developmental Disabilities*. 25: 245-264
- [13] Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. 2013. Respite Care, Marital Quality, and Stress In Parents of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*. 43(11): 2604-2616.
- [14] Jones, L., Hastings, R. P., Totsika, V., Keane, L., & Rhule, N. 2014. Child Behavior Problems and Parental Well-Being in Families of Children with Autism: The Mediating Role of Mindfulness and Acceptance. *American Journal on Intellectual and Developmental Disabilities*. 119(2): 171–85. <http://doi.org/10.1352/1944-7558-119.2.171>
- [15] Nikmat, A.W., Ahmad, M., Oon, N.G., Razali, S. 2008. Stress and Psychological Well Being among Parents of Children with Autism Spectrum Disorder. *ASEAN Journal of Psychiatry*. 9(2): 65-72.
- [16] Wang, P., Michaels, C. A., & Day, M. S. 2011. Stresses and Coping Strategies of Chinese Families with Children with Autism and Other Developmental Disabilities. *Journal of Autism and Developmental Disorders*. 41(6): 783-795.
- [17] Central Intelligence Agency 2012. Retrieved 17 May 2012. The World Fact Book: Malaysia. <https://www.cia.gov/library/publications/the-world-factbook/geos/my.html>
- [18] 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 Disorder*. 7(7): 858-865.
- [19] Green, J. C., & Caracelli, V. J. (Eds.). 1997. Advances in Mixed-Method: The Challenges and Benefits of Integrating Diverse Programs. *New Directions for Evaluation (74)*. San Francisco: Jossey-Bass
- [20] Teddlie, C., & Tashakkori, A. .2009. *Foundations of Mixed Methods Research: Integrating Quantitative and Qualitative Approaches in the Social and Behavioral Sciences*. Sage Publications Inc.
- [21] Karst, J. S., & Van Hecke, A. V. 2012. Parent and Family Impact of Autism Spectrum Disorders: A Review and Proposed Model for Intervention Evaluation. *Clinical Child and Family Psychology Review*. 15(3): 247–77.
- [22] Kim, Y. S., Leventhal, B. L., Koh, Y. J., Fombonne, E., Laska, E., Lim, E.-C., Grinker, R. R. 2011. Prevalence of Autism Spectrum Disorders in a Total Population Sample. *The American Journal of Psychiatry*. 168(9): 904–912.
- [23] 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(2): 37-47.
- [24] Kee, Yeo and Lu Xi. 2012. Factors Associated with Diagnosis of Autism Spectrum Disorder (ASD) under the Age of 24 Months in Malaysia. *Jurnal Teknologi*. 58: 79–83.
- [25] Rivers, J. W., & Stoneman, Z. 2003. Sibling Relationships When a Child Has Autism: Marital Stress and Support Coping. *Journal of Autism and Developmental Disorders*. 33(4): 383-394.
- [26] Quintero, N., & McIntyre, L. L. 2010. Sibling Adjustment and Maternal Well-Being: An Examination of Families With And Without An Autism Spectrum Disorder. *Focus On Autism And Other Developmental Disabilities*. 25(1): 37-46.
- [27] Osborne, L. A., McHugh, L., Saunders, J., & Reed, P. 2008. Parenting Stress Reduces the Effectiveness of Early Teaching Interventions for Autistic Spectrum Disorders. *Journal of Autism and Developmental Disorders*. 38: 1092-1103.
- [28] Taha, G. R., & Hussein, H. 2014. Autism Spectrum Disorders in Developing Countries: Lessons from the Arab World. In V. B. Patel, V. R. Preedy, & C. R. Martin (Eds.). *Comprehensive Guide to Autism*. 2509-2531. New York: Springer.
- [29] 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(12): 874-882.

- [30] Hedda, M., James, W. H., Aaron, T. E. 2010. Families with Children Who Have Autism Spectrum Disorders: Stress and Support. *Exceptional Children*. 77(1): 7-36.
- [31] Daley, T. C. 2004. From Symptom Recognition to Diagnosis: Children with Autism in Urban India. *Social Science and Medicine*. 58(7): 1323–1335.
- [32] Bahari, S. F. 2012. Qualitative Versus Quantitative Research Strategies: Contrasting Epistemological and Ontological Assumptions. *Jurnal Teknologi*. 52(1): 17–28.
- [33] Bryman, A. 2006. Paradigm Peace And The Implications For Quality. *International Journal of Social Research Methodology*. 9(2): 111-126.
- [34] Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. 2007. Toward a Definition of Mixed Methods Research. *Journal of Mixed Methods Research*. 1(2): 112–133. <http://doi.org/10.1177/1558689806298224>
- [35] Bryman, A. 2007. Barriers to Integrating Quantitative and Qualitative Research. *Journal of Mixed Methods Research*. 1(1): 8–22. doi: 10.1177/2345678906290531
- [36] Bazeley, P. 2010, July. Metaphors for Integrated Analysis in Mixed Methods Research. *6th International Mixed Methods Conference, Baltimore, USA*.
- [37] Odom, S. and Collet-Klingenberg, L. 2010. Evidence-Based Practices in Interventions for Children and Youth With Autism Spectrum Disorders. *Preventing School Failure: Alternative Education For Children And Youth*. 54(4): 275-28.
- [38] Creswell, J. W. 2007. *Qualitative Inquiry and Research Method: Choosing Among Five Approaches*. 2nd. ed. Thousand Oaks, CA: Sage.
- [39] Charmaz, K. 2000. Constructivist and Objectivist Grounded Theory. In. N. Denzin and Y. Lincoln (Eds.). *Handbook of Qualitative Research*. Thousand Oaks, CA: SAGE Publications Inc.
- [40] Charmaz, K. 2006. *Proto Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London: Sage Publications Ltd.
- [41] Allen, L. M. 2010. A Critique of Four Grounded Theory Texts. *The Qualitative Report*. 15(6): 1606-1620.
- [42] Onwuegbuzie, A. J., & Collins, K. M. T. 2007. A Typology of Mixed Methods Sampling Designs in Social Science Research. 12(2): 281–316.
- [43] Onwuegbuzie, A. J., & Johnson, R. B. 2004. Mixed Method And Mixed Model Research. In R. B. Johnson & L. B. Christensen. *Educational Research: Quantitative, Qualitative, and Mixed Approaches*. 408-431. Needham Heights, MA: Allyn & Bacon.
- [44] Burton, L. J., and Mazerolle, S. M. 2011. Survey Instrument Validity Part 1: Principle of Survey Instrument Development and Validation in Athletic Training Education Research. *Athletic Training Education Journal*. 6(1): 27-35.
- [45] Guest, G., Bunce, A., & Johnson, L. 2006. How Many Interviews Are Enough? An Experiment with Data Saturation and Variability. *Field Methods*. 18: 59-82.
- [46] Sandelowski, M. 2001. Real Qualitative Researchers Do Not Count: The Use of Numbers in Qualitative Research. *Research in Nursing & Health*. 24(3): 230-240.
- [47] Tabachnick, B. G., & Fidell, L. S. 2013. *Using Multivariate Statistics*. 6th Ed. New York, Harper Collins.
- [48] Glaser, B. S., & Strauss, A. A. 1967. *The Discovery of Grounded Theory*. New York.
- [49] Ivankova, N. V. & Stick, S. L. 2007. Students' Persistence in a Distributed Doctoral Program in Educational Leadership in Higher Education: A Mixed Methods Study. *Research in Higher Education*. 48(1): 93-135.
- [50] Brereton, A.V., Tonge, B.J., Mackinnon, A.J. & Einfeld, S.L. 2002. Screening Young People for Autism with the Developmental Behaviour Checklist. *Journal Of The American Academy of Child & Adolescent Psychiatry*. 41(11): 1369&–375. Giallo, R., Wood, C. E., Jelleff, R., & Porter, R. 2013. Fatigue, Wellbeing and Parental Self-Efficacy in Mothers of Children with an Autism Spectrum Disorder. *Autism*. 17: 465–480.
- [51] Constantino, J. N., Gruber, C. P. 2012. *The Social Responsiveness Scale Manual, Second Edition (SRS-2)*. Los Angeles, CA: Western Psychological Services.
- [52] Frazier, T. W. , Ratliff, K. R., Gruber, C., Zhang, Y., Law, P. A., & Constantino, J. N. 2014. Confirmatory Factor Analytic Structure and Measurement Invariance of Quantitative Autistic Traits Measured by the Social Responsiveness Scale-2. *Autism*, 18: 31-44. doi:10.1177/1362361313500382
- [53] Lovibond, S. H., & Lovibond, P. F. 1995. *Manual for the Depression Anxiety Stress Scales 2nd Edition*. Sydney: Psychology Foundation.
- [54] Epstein, T., Saltzman-Benaiah, J., O'Hare, A., Goll, J. C., & Tuck, S. 2008. Associated Features of Asperger Syndrome and Their Relationship to Parenting Stress. *Child Care Health Development*. 34(4): 503–511.
- [55] Byles, J., Bryne, C., Boyle, M., & Offord, D.R. 1988. Ontario Child Health Study: Reliability and Validity of the General Functioning Subscale of the McMaster Family Assessment Devic. *Family Process*. 27: 97–104.
- [56] Abidin, R.R. 1995. *Parenting Stress Index, 3rd ed*. Odessa, FL: Psychological Assessment Resource.
- [57] Buysse, D. J., Reynolds, C. F., Monk, T. H., Berman, S. R., & Kupfer, D. J. 1988. The Pittsburgh Sleep Quality Index: A New Instrument for Psychiatric Practice and Research. *Journal of Psychiatric Research*. 28: 193–213.
- [58] Bailey, J. 2008. First Steps In Qualitative Data Analysis: Transcribing. *Family Practice*. 25(2): 127-131.
- [59] Johnson, R. B., & Onwuegbuzie, A. J. 2004. Mixed Methods Research: A Research Paradigm Who's Time Has Come. *Educational Researcher*. 33(7): 14–26. <http://doi.org/10.3102/0013189X033007014>