

STRESS MANAGEMENT STRATEGIES FOR PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

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Stress is a common problem among parents; many studies have shown that those who have children with Autism Spectrum Disorder (ASD) are at a higher level of stress and other mental health problems. In Malaysia, however, most of the available treatments, guidelines and policies from the government are only directed toward the needs of the children, and less consideration is given to the needs of the parents. For example, the Disabled Persons Policy by the Malaysian Ministry of Women, Family and Community Development (2016) only focused on the child's welfare and not the parents. Therefore, it was the main objective of this study to provide stress management strategies for Malaysian parents of children with ASD to minimise their stress. The study involved mixed method design, and it consisted of 2 phases: 1) examining the stress level of parents of children with ASD (quantitative), and 2) developing stress management strategies for parents (qualitative). In Phase 1, Parenting Stress Index Fourth Edition (PSI-4) was distributed to obtain the quantitative data. Meanwhile, in Phase 2, focus group interview were conducted to obtain qualitative data. The study found that stress among parents is reaching toward the high level. The qualitative result of this study had generated various stress management strategies, such as seeking social support, and early intervention.

Keywords: Autism spectrum disorder, parenting stress, stress management, parenting guidelines

INTRODUCTION

Stress is a common experience for every parent; however previous studies have shown that parents of children with Autism Spectrum Disorder (ASD) have a higher stress level compared to parents of typically developed children, and children with other disabilities (Hayes & Watson, 2013; Lee, Ong, Lee, & Fairuz Nazri, 2017). Moreover, they are also at a higher risk of clinical disturbances

such as depression and anxiety (Al-Farsi, Al-Farsi, Al-Sharbati, & Al-Adawi, 2016; Almansour, Alateeq, Alzahrani, Algeffari, & Alhomaïdan, 2013). This condition also occurs among Malaysian parents, as shown by local findings by Lee, Ong, Lee, and Fairuz Nazri (2017). The process of acceptance among parents, especially the mother is very challenging (Kermanshahi et al., 2008). Kermanshahi et al. (2008) added that “painful emotional reactions, the inter-relatedness of the mother’s health and the child’s well-being, struggles to deal with oneself or the child, inadequate support from the family and community, and anxiety related to the child’s uncertain future” are commonly seen among parents of children with disabilities, including parents of children with ASD. Hence, this current study aims at providing stress management and strategies that parents of children with ASD can refer to and to put these strategies to practice. This is to prevent serious mental health problems among them, and subsequently assist with their well-being.

LITERATURE REVIEW

Studies indicate that parents of children with ASD experience both acute and chronic stress (Dyken, & Lambert, 2013; Gallagher, Phillips, Drayson & Carroll, 2009; Solomon & Chung, 2012). According to the American Psychological Association (APA, 2017), acute stress is defined as short-term stress resulted from demands and pressures in the past, and near future. Acute stress is treatable, but it can cause an individual to be emotionally distressed, experience muscular problems (e.g., tension headache, back pain), stomach, gut, and bowel problem (e.g., heartburn, flatulence), and brief over- arousal that lead to rise in blood pressure and related problems (APA, 2017). A study indicates that parents for a child with disabilities reported higher physical symptoms, such as aches in different parts of the body, gastrointestinal problem, and upper respiratory symptoms due to the acute stress (Seltzer et al., 2009).

Meanwhile, chronic stress refers to a long-term stress condition caused by unrelenting demands and pressures (APA, 2017). Unlike acute stress, it can be fatal and difficult to treat. This type of stress is associated with serious mental health disorders, such as anxiety and depression (Khan, & Khan, 2017; Mariotti, 2015), and negative physical health outcome (Arthur, 2001; Salleh, 2008). It is alarming that many parents of children with ASD show presence of depression and anxiety symptoms (Al-Farsi, Al-Farsi, Al-Sharbati, & Al-Adawi, 2016; Almansour, Alateeq, Alzahrani, Algeffari, & Alhomaïdan, 2013), and poor health condition, with poor antibody response (Fairthorne, Klerk, & Leonard, 2015).

STATEMENT OF PROBLEM

Parents of children with ASD in ASEAN countries, including Malaysia receive little to no assistance in their daily life, which can cause their stress level to increase. This can be due to the lack of policy and financial aid for the special needs and mental health area (as cited by Ilias, Cornish, Kummar, Park, & Golden, 2018). As stated previously, high stress level may lead to a more adverse effect on one's mental and physical health. This is considered as a serious concern that needs to be addressed properly. Moreover, most of the existing policies towards the families of child with disabilities in Malaysia are only providing assistance for the child's needs, such as the Disabled Persons Policy by the Malaysian Ministry of Women, Family and Community Development (2016). Less attention and support have been given to the parents. Parents are not provided with much guidance to manage their children with disabilities better, or even to manage themselves better. On top of that, parenting children with ASD is different from parenting typically-developed children. Thus, parents of children with ASD will need specific strategies to manage their stress. The specific strategies may help to improve the parenting skills of these parents. Therefore, this study focuses on the strategies to manage stress among parents of children with ASD.

CONCEPTUAL FRAMEWORK

The study refers to the conceptual framework of Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984). This theory can help to provide strong explanation on the role of cognitions and appraisals involved in parental stress. The transactional model (1984) suggests that stress is a product of transaction between a person, which includes his or her cognitive, physiological, affective, psychological and neurological aspects, and his or her complex environment. According to Lazarus (1966), the individual's appraisal of stress will determine how the individual will cope with the stressors. In this model, Lazarus and Folkman (1984) elaborated more on the concept of stress appraisal by categorising it into primary appraisal, and secondary appraisal.

The primary appraisal involves the individual to determine whether a stressor signifies a threat. The secondary appraisal involves the individual's evaluation on how to deal with the stressors based on the available resources or coping strategies. This model provides two categories of coping style, which are problem-focused and emotion-focused coping strategies. Both these strategies attempt to alleviate the stress caused by the stressors. Problem-focused coping refers to action that directly alters the elements of stressful situations while emotion-focused coping refers to the effort to reduce negative emotional response related to the stress.

OBJECTIVES

The present study intended to improve the life of parents of children with ASD by reviewing and discussing suitable stress management strategies for this group. The study will also examine parenting stress level. The purpose was to identify whether the finding is consistent with the previous findings, which will be discussed in the discussion section.

METHODOLOGY

Design

The research was conducted by adopting a mixed method research design, specifically the sequential explanatory design, in which the quantitative data were first collected, followed by the qualitative data. The quantitative method was used to obtain descriptive data on the stress level among the respondents, which was obtained through self-report questionnaires. The qualitative method was used to obtain data on the stress management and strategies that are helpful for the parents. The qualitative data are the main data for the study, and they were obtained through focus group discussion.

Respondents

The sample consisted of 52 Malaysian parents of children with ASD below 13 years old who had completed the Parenting Stress Index Fourth Edition (PSI-4) and Gilliam Autism Rating Scale Third Edition (GARS-3). The respondents were contacted via third parties, such as autism centres in the Klang Valley, and through freelance therapists. Some of them were contacted directly by the researcher. For each child, only one of the parents is needed to complete the questionnaire.

Meanwhile, the study also recruited participants for a focus group discussion. The members consisted of four people; the director of GENIUS Kurnia, a representative from Insani Autism Academy who is also a parents of child with ASD, and two officers from the Ministry of Education (MoE).

Procedure

The study involved 2 phases: 1) assesses the stress level of parents of children with ASD, and 2) construct stress management strategies for parents of children with ASD. In the First Phase, the researcher emailed to ten different autism centres in Klang Valley to request for permission to collect quantitative data for the current study. Only two out of ten centres accepted the request. After

obtaining permission, the researcher set a date to visit the centres to distribute the questionnaires which consist of the PSI-4 and GARS-3. The researcher passed the questionnaires to the teachers or therapists at the centres, and they distributed them to the parents. The parents were allowed to complete the questionnaires at home, and were asked to return them to the centre after two weeks. A total of sixty questionnaires were distributed to both centres (thirty questionnaires for each), but only thirty-two questionnaires were returned in a complete form. The researcher then had to collect more data from other parents directly from friends, friends of friends, family members, or through freelance autism therapists. The researcher managed to obtain twenty more completed questionnaires, and this accumulated to a total of fifty-two completed questionnaires. After completion of the questionnaire in the collection phase, the data were keyed into SPSS software for analysis.

In the Second Phase, a 2-hour focus group discussion was conducted with the MoE officers, GENIUS Kurnia director, and Insani Autism Academy representative to discuss the stress management strategies for parents of children with ASD. The discussion was recorded and key points from it were noted down for further analysis. The thematic analysis as suggested by Braun and Clarke (2006) was used. This method involves “identifying, analysing, and reporting patterns (themes) within data” (Braun & Clarke, 2006).

RESULTS

Phase 1

In order to determine stress level, the percentile rank of the PSI-4 Total Stress score is referred. The descriptive analysis was conducted for this purpose. The result of the analysis shows that the average percentile rank of the PSI-4 Total Stress score was 74.42 ($SD = 20.10$). The score fell in the normal range, which is between 15 to 80.

Phase 2

The findings from the focus group discussion yielded three stress management strategy themes, which are:

Encourage early intervention. One of the focus group members suggested that parents should send their child for early intervention as early intervention may increase the improvement rate of the child. This suggestion was agreed by the rest of the group members. The following excerpts were translated from Malay to English.

“...parents are encouraged to send their child for treatment, the earlier the better...based on researches, there are high chances for the child to function better.”

(Member 1)

Provide a quality and comprehensive training on special needs for counsellors.

The members suggested that the counsellors, especially those working with parents should be provided with quality and comprehensive training on special needs.

“It is necessary for the counsellors to have knowledge in the special needs area, it is high likely that they will encounter parents of children with special needs as their clients.”

(Member 2)

“...provide training for counsellors in this field (special needs), so that they are able to cater to the parents’ needs, and understand them better.”

(Member 3)

Provide a quality and comprehensive training for special needs teachers and educators. All of the members reached a consensus that there is a need for special needs teachers to be highly trained in their field in order to provide quality service to both parents and children.

“...children spend more time in school than at home. Teachers should ensure that they (children with autism spectrum disorder) receive good intervention in school.”

(Member 1)

“Special education teachers should be given comprehensive training on special needs areas...to enhance their skills.”

(Member 2)

“Children who receive good intervention from their teachers may have less behaviour problem, this in turn may contribute to less stress in parents.”

(Member 4)

DISCUSSION

Phase 1

According to the PSI-4 manual, the normal stress level is between percentile rank of 15 to 80 (Abidin, 2012). Based on the result from the study, Malaysian parents of children with ASD are found to have normal stress level. This current finding seemed to be inconsistent with the previous findings (Al-Farsi et al., 2016; Almansour et al., 2013; Lee et al., 2017). However, despite being in the normal range, the score is nearly reaching the high stress level. Hence, proactive measures still need to be taken in preventing serious mental health problems among these parents. This result also supports the current study's initiative to develop stress management strategies for parents of children with ASD.

Phase 2

The focus group discussion had revealed different stress management strategies. The findings fit into the Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984), whereby both solution and emotion-focused coping were involved. The findings will be discussed separately.

Focus Group Discussion Strategies

The focus group discussion had resulted in recommendations directed at the authorities, such as the government, in the effort to improve the well-being of the parents. The recommendations are:

Encourage early intervention programme for the child. The focus group has agreed that early intervention programme can help to increase the chance of better functioning in the child, which in turn can decrease parenting stress. The government can assist parents by providing subsidy or create awareness on the need for early intervention. As cited in the review study by Zwaigenbaum et al. (2015), early intervention will not only give positive impact on the child, but to the parents as well.

Provide a quality and comprehensive training on special needs for counsellors. The focus group suggested that highly skilled and trained counsellors can give a better service to the parents. This includes providing accurate information to the parents, demonstrating a good understanding of the challenges they face, and being able to give good alternatives for them. Therefore, a proper and comprehensive training on special needs should be made compulsory to counsellors. Fareo (2015) also stated that professionals including counsellors, play an important role in supporting parents or families of children with special

needs. Hence, they are required to be professional and competent to handle these clients.

Provide a quality and comprehensive training for special education teachers. The focus group recommends that teachers and educators who work with children with special needs, especially children with ASD, need to be trained with proper skills and knowledge. This will enable them to deliver an efficient and effective service to the child, which can help to improve the child's condition. Subsequently, the effect of this may lower the stress level in parents. A study by Hendricks (2011) also addressed the needs for special educators to be fully equipped with skills and strategies to assist students with ASD.

Literature Review Strategies

The findings from the focus group discussion strategies may be somewhat different than the review of literature. The strategies are:

Seeking social support from family and friends. Many studies found positive impacts of family and friends' social support on parents of children with ASD. One of the impacts is to increase the parents' optimism, which can in turn decrease stress level (Ekas, Lickenbrock, & Whitman, 2010). In addition, social support is also shown to be a good buffer from adverse health in parents of children with ASD (Lovell, Moss & Wetherell, 2012).

Joining parent support group. Parent support group can help parents to increase their self-efficacy, and make them feel empowered (Clifford & Minnes, 2013a). Moreover, support groups can increase adaptive coping strategies in parents (Banach, Iudice, Conway, & Couse, 2010). Another study also showed that online support groups are perceived as helpful for parents of children with ASD, although it may not significantly impact their stress level (Clifford & Minnes, 2013b). One of the support groups available in Malaysia is Parents' Resource for Autism Malaysia (pr4a), while the biggest online support group for parents of children with ASD in Malaysia is the Facebook page 'Autisme Malaysia'.

Practice mindfulness. Previous studies revealed a significant reduction in parental stress level through mindfulness techniques (Cachia, Anderson, & Moore, 2016; Conner & White, 2014). Parents also reported improvements in their parenting role after practising mindfulness (de Bruin, Blom, Smit, van Steensel, & Bögels, 2015). A prominent mindfulness technique includes the experiential practice, which involves breath awareness and body scan.

Using adaptive coping style. A significant stress reduction is associated with positive reappraisals (Rayan & Ahmad, 2017) and task-oriented coping (Dabrowska & Pisula, 2011; Kiami & Goodgold, 2017). Positive reappraisals involve changing one's perspective into a positive manner when dealing with a difficult situation, while task-oriented coping involves putting effort to solve the problem by directly altering the situation, or attempting cognitive restructuring.

Adopting the authoritative parenting style. Authoritative parenting style involves a high responsiveness to the child's needs, and at the same time setting a proper boundary to discipline the child. A study recommends that authoritative parenting is the most effective parenting especially when caring for children with ASD (Tripathi, 2015). Parents of children with ASD also reported higher resilience when practicing this parenting style (Sinha, Verma & Hershe, 2016).

CONCLUSION

This present study found that the stress level of parents of children with ASD is normal, but almost reaching the high level. Hence, proactive measures are needed to prevent parents from developing more serious mental health issues. The focus group discussion from the study also resulted in recommendations in improving the well-being of parents, as well as improving the services for parents.

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