

Parenting Stress among Parents of Children with Autism Spectrum Disorder: The Need of Stress Management Guidelines and Policy

Noor Aishah Rosli*
Zarinah Mohd Kasirun
Mohd Hairul Nizam Md Nasir
Fazidah Othman
Tengku Sarina Aini Tengku Kasim

*Department of Educational Psychology and Counselling, Faculty of Education,
Universiti Malaya*

*Corresponding e-mail: [aishahr@um.edu.my]

This concept paper reviews the issue of parenting stress in mothers and fathers of children with Autism Spectrum Disorder (ASD), and highlights the need for stress management guideline and policy for these parents in Malaysia. Many studies have shown that parents of children with ASD are experiencing a high level of stress. Despite this issue, there has not been any local measures to improve the well-being of the parents. In Malaysia, there is no policy or standard guideline for parents of children with ASD, hence maintaining the risk of mental health cases among them. In order to overcome this issue, this paper reviewed the Lazarus and Folkman's (1984) problem-focused strategies used by parents of children with ASD from previous studies. The strategies mentioned in this paper had been empirically proven as reducing the parents' stress level. This paper also recommends the strategies to be included in a local policy to help the parents manage their stress.

Keywords: autism, stress, children, parenting, PSI-4

Stress is a common experience for parents, however past researches had revealed that parents of children with Autism Spectrum Disorder (ASD) experienced higher level of stress compared to parents of typical children (Hayes and Watson, 2013; Padden and James, 2017), and even parents of children with other disabilities (Valicenti-McDermott et al., 2015). Caring for children with ASD can be highly stressful for parents as they require extra attention and support (Dabrowska and Pisula, 2010), may have behavior problems (Miranda, Mira, Berenguer, Rosello, and Baixauli, 2019), and lack of social skills (Pisula, 2011). A study conducted in Malaysia revealed a consistent finding, in which

parents of children with ASD experience a high stress level (Lee, Ong, Lee and Fairuz Nazmi 2017). In addition, 53.8% of Malaysian parents of children with ASD had presence of clinical disturbance in psychological wellbeing (Nikmat, Ahmad, Oon and Razali, 2008). In latest studies, similar results were found, in which parents of children with ASD display clinical symptoms, such as depressed feelings (Ilias, Liaw, Cornish, Park, and Golden, 2017; Manan, Amit, Said, and Ahmad, 2018). Meanwhile, The National Autism Society of Malaysia (NASOM) had reported that there had been an increase in the number of intake of children with ASD in their organization (Kaur, Engakasa,

Sivanesom and Kamarudin, 2015). This report indirectly shows an increase in awareness of ASD, however it also suggests that more parents are potentially at risk of high stress level.

Despite the potential mental health risk that had been widely reported, there has still been a lacking in stress management guidelines and policy for parents of children with ASD, especially in Malaysia. Hence, it is the objective of this paper to raise the awareness on the need of a stress management guidelines and policy for parents of children with ASD. This paper will also recommend effective strategies that can help to reduce stress for parents of children with ASD, and subsequently lead to a better policy for parents of children with ASD in Malaysia.

Disabled Policy in Malaysia

Malaysia is among the countries that have ratified the Convention on the Rights of Persons with Disabilities adopted by the United Nations General Assembly (Rehman, 2009). This convention was made to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity' (Schulze, 2010). By ratifying this convention, it indicates that the government recognizes the right of persons with disabilities. On top of that, the government has also authorized the Persons with Disabilities Act 2008, in which it acknowledges the contribution made by persons with disabilities to the country (Abdullah, Hanafi and Hamdi, 2017). Other effort made by the Malaysian government to assist individuals also include the Disabled Persons Policy developed by the Ministry of Women, Family and Community Development, Malaysia (2016). Under this policy, there are different strategies that aim towards the betterment of people with disabilities. Such

strategies include improving health services for the disabled, improving the public facilities for disabled, and increasing their access to education (Ministry of Women, Family and Community Development, Malaysia, 2016).

With these existing policies, it is assured that the government is showing concern and commitment towards the rights and well-being of persons with disabilities. However, these policies have not considered the importance of the parents' well-being. These policies are mainly targeted towards the well-being of the child or persons with disabilities, without providing any guidelines to support the well-being of the parents. Furthermore, Malaysia is not the only country that lack of policy or guidelines to support parents of children with disabilities. A similar situation also occurs in the United States and Japan, in which the focus of their policy is more directed towards supporting the well-being of the disabled children, without giving proper attention to the support required by their family (Grossman and Magaña, 2016; Kobayashi, Inagaki and Kaga, 2012). This is a gap that needed to be filled in. These parents face daily challenges to raise their disabled children with little or no guidance, which can be stressful for them. Additionally, there is no specific guidelines that has been structured for parents of children with ASD, considering that they are at the highest risk of mental health issues. Therefore, this paper strongly suggests the need of a structured guidelines and policy that constitutes effective stress management strategies for parents of children with ASD.

Stress Management Strategies

The proposed stress managements strategies will be based on problem-focused coping as suggested by Lazarus and Folkman's (1984) transactional stress and coping theory. Problem-focused coping refers to the action that directly alters the

elements of the stressful situations (Lazarus and Folkman, 1984). Previous studies have shown that problem-focused coping has been associated with many positive outcome and improvements in parents' well-being (Kiami and Goodgold, 2017; Pourmohamadreza-Tajrishi, Azadfallah, Garakani, and Bakhshi, 2015).

Use of visual supports

Communication problem can be very stressful for both the parents and children with ASD. Therefore, the use of visual supports such as drawings, pictures, and written words, is suggested to improve the child's functional communication, and also to teach appropriate behavior and skills. This is because children with ASD are shown to be more responsive to visual information than auditory information (Kurniawan, 2018), hence any verbal communication delivered together with visual support will make it easier for them to comprehend. Visual supports such as social stories, and video modelling are useful to teach appropriate behavior and skills. A social story is a short story written in a first-person view to teach the child about a specific social skill, behavior, rule, concept, or event (Bohlander, Orlich and Varley, 2012). In the social story, there will be description about what, when, where, and why a skill, behaviour, rule, concept, or event will occur, and the expected skill or behavior that the child needs to display (Gray, 2000). For example, if the parents want to teach the child about playing nicely with siblings, they can include description on joining other siblings at play time, sharing toys, and taking turns at play, and explain the importance and result of this appropriate behavior. A video model is also similar to social story, except that it is done in a video format. Study suggests that using visual supports appear to be an evidence-based method to improve the skills of students with ASD (Wong et al., 2015). Besides that, a visual schedule is designed to inform the child on the sequence of

upcoming activities or events through pictures, drawings, or written words (Meadan, Ostrosky, Triplett, Michna, and Fettig, 2011). Studies have shown that the use of visual schedule has helped to enhance a child's independence (Pierce, Spriggs, Gast, and Luscre, 2013; Wong et al. 2015). Based on the evidence provided, visual supports can be helpful tools for parents to communicate better with their child, and subsequently help to reduce their stress. Therefore, a policy should include providing parents of children with autism with visual supports, and also training them to use the visual supports.

Behaviour prevention and management

Parents often feel helpless when their child is throwing tantrums or having meltdowns. Studies have shown that there is a transactional relationship between parenting stress and child behaviour problem (Neece, Green, and Baker, 2012; Rodriguez, Hartley, and Bolt, 2019). Another study suggests that parents who are able to handle their child's challenging behaviors can cope with stress better (Feather, 2015). The problem behavior can probably be due to frustration in many areas, such as lack of communication ability, and inflexibility to changes. Hence, parents need to identify the potential triggers to the child's behavior in order to prevent any behavior from occurring.

The Antecedent-Behaviour-Consequence (ABC) technique is useful to help parents to identify the pattern and functions of the child's behavior problem (Absoud, Wake, Ziriati, and Hassiotis, 2019). The ABC technique requires the parents to observe the behavior displayed by the child, the event that happens prior to the behavior, and the consequence following the behavior (Absoud, Wake, Ziriati, and Hassiotis, 2019). This will help the parents to keep track of what is triggering and maintaining the child to behave in a certain manner, and consequently prevent such behavior from

happening. For example, the displayed behavior is screaming when there is a loud noise in the house, and the consequence is redirecting the child with a tablet game. From this example, the parents can identify that the loud noise is triggering the screaming behavior, and the behavior is reinforced by the presence of tablet. By being able to identify this pattern, parents can either change the trigger, or the consequence to the child's behavior. Besides that, the ABC chart is also useful to keep track of the child's appropriate behavior, and consequently reinforce the behavior. Consistent with the operant conditioning concept by Skinner (1966), positive reinforcement or reward will increase the occurrence of one's behavior. Hence, parents can reward their child when they engage in an appropriate manner, so that the behavior will continue to increase. Therefore, policy-maker should consider providing parent training, specifically on behavior management and prevention aspects for parents of children with autism. This will improve parents' competence in managing their child, and also help them to handle their stress better.

Mindfulness techniques

Mindfulness refers to the "the awareness that emerges through paying attention, on purpose, in the present moment, and nonjudgmentally to the unfolding of experience moment by moment" (Roemer, Williston and Rollins, 2015). According to Cresswell (2017), mindfulness has been associated with positive "mental and physical health, cognitive and affective factors, and interpersonal outcome". Moreover, it can also help with chronic pain management, and lower the relapse rate of depression (Cresswell, 2017). Studies also revealed a significant reduction in parental stress level with the practice of mindfulness techniques (Conner and White, 2014; Cachia, Anderson and Moore, 2016). A prominent mindfulness technique includes the experiential practice, which involves

breath awareness and body scan (Bluth, Roberson, Billen and Sams, 2013). The former involves paying attention to the breath and redirect the attention when attention is lost (Bluth et al., 2013). Meanwhile, body scan requires paying attention to the body's physical sensation, which begins from the toes and up to the head (Bluth et al., 2013). The findings from previous studies have shown many positive outcomes of the mindfulness practice. A policy for parents of children with autism should encourage parents to attend Mindfulness-Based Stress Reduction (MBSR) therapy for a professional mindfulness training. The MBSR therapy should be provided for free for the parents to attend.

Online support group

Previous study found that social support has a positive relationship with well-being (Halstead, Griffith and Hastings, 2017). Furthermore, social support is shown to be essential to reduce the stress level of parents with autistic children (Smith, Greenberg and Seltzer, 2012). Involving in a support group is a helpful way for parents to obtain great social support. According to a study on parents support groups, participants reported to feel more comfortable, and less judged and discriminated in the group (McCabe and McCabe, 2013). This indicates that such support group may help the parents to feel more positive and optimistic with their life. Support groups are not only accessible in a face-to-face context, but also via online social network. The online group support is more accessible for parents who have time constraint. There has been an increasing growth of Facebook group page for parents of children with ASD in Malaysia, such as Autisme Malaysia Public Group. A study found that parents are open to share about their personal experience in the Facebook group page (Mustafa et al., 2015), which can be very helpful for other parents. Moreover, the group page is interactive and

informational, as members are very responsive to any question that is posted in the group page (Mustafa, Short and Fan, 2015). Another study in Malaysia also revealed that there is a high exchange in information and emotional support in the facebook community among families of children with ASD (Roffeei, Abdullah, and Basar, 2015). These evidences support the finding by Ammari and Schoenebeck (2015) stating that the effect of parent support group in Facebook enhance the parents' network empowerment, in which parents are able to connect with other parents, gain resources, and discover new strategies to promote healthy lifestyle among them. Thus, the online support group for parents of children with ASD can assist parents to engage in a more positive emotion, and reduce negative emotion. In order to make this strategy works, a standardized social network page should be set up and managed by a professional. Then, the policy should encourage parents to register themselves and participate in the discussion or information posted in the page.

Discussion

This paper aimed to review the needs of stress management guidelines and policy for parents of children with ASD, and also to suggest empirically-supported strategies to manage stress for parents. The paper had proposed four strategies, which are: 1) using visual aid to communicate with the child, 2) applying behavior prevention and management techniques, 3) practicing mindfulness, and 4) engage in online support group. Previous studies have shown that these strategies are effective in reducing parental stress. Moreover, the strategies proposed are convenient for every parent to practice as it does not involve complex tools or instrument. For example, parents can print out social stories from online websites for free. Otherwise, they can draw out the social stories in a simple manner. Besides that, the proposed

behavior prevention and management techniques are also achievable because parents only need to monitor and modify the consequence or triggers to their child's behavior. Mindfulness techniques mentioned in this paper are simple for every parent to practice at home, which are suitable to prevent and cope with stress. Lastly, engaging in online social support group is a way for parents to connect with other parents with similar situation and obtain useful information or encouragement from each other. This strategy is convenient because parents can access the internet at any time, and anywhere. However, this strategy may be limited to parents who have access to internet only. Another suggestion to replace this strategy is by attending face-to-face social support group.

Conclusion

Parents of children with ASD experience more stressful events compared to parents of typical children and other disabilities. However, the current support programs and policies in Malaysia are insufficient to lessen the stress of these parents. Therefore, the stress management strategies proposed in this paper may help to build a better policy for parents of children with ASD. The proposed strategies will assist parents to manage their stress better, and subsequently promote a healthier parenting.

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