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The effect of psychoeducation on parents of autistic children in Malaysia

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ABSTRACT

Parents have reported a lack of support from professionals in Malaysia, which results in a lack of knowledge in supporting their children, leading to negative attitudes towards their child's condition, a lack of empowerment, and psychological problems. This study aimed to determine the effect of psychoeducation on the knowledge, attitude, empowerment, and psychological well-being of parents of children with autism spectrum disorder (ASD). The design of this study was true experimental design. The study focused on parents of ASD-diagnosed children aged 2 to 7 years. Nineteen parents participated and were randomly allocated to the intervention group and control group. Pre and post-tests questionnaires assessed knowledge, attitude, psychological well-being, and empowerment. Independent and paired t-tests were used for data analysis. The results showed that there were no significant differences between the control and intervention groups in their knowledge (t(17)=-.186, p=.854), attitude (t(14.9)=1.26, p=.227), psychological wellbeing (t(13.44)=.221, p=.828) and empowerment (t(15.45)=.047, p=.96). There were no significant differences in the pre and post-sessions of the knowledge (t(9)=1, p=.329), attitude (t(9) =.536, p=.605), and psychological well-being (t(9)=.67, p=.521). However, there was a significant difference in the pre and post-session parent's empowerment (t(9)=-2.5, p=.032). These findings suggest that other interaction factors may affect the effectiveness of psychoeducation sessions in parent's knowledge, psychological wellbeing, attitude, and empowerment.

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1. INTRODUCTION

The prevalence of children with autism spectrum disorder (ASD) has increased, in Malaysia [1], [2]. Due to stigma and low levels of awareness among the general population, it leads to a lack of diagnosis [3], [4]. Therefore, most children may go untreated until they reach school age and when teachers bring out the "red flag" to parents [2]. ASD is a neurodevelopmental disorder and lifelong condition. The child with ASD has shown deficits in social communication, interaction and restricted and repetitive behavior which requires a different level of support [5], [6]. Parents with children with ASD are shown to experience more stress and distress compared to parents with typical children or other type of neurodevelopmental disorders [4]. Parents' knowledge and involvement are crucial in dealing with their special needs child, with a lack of social support leads to extreme stress for parents and family members to adapt and cope with the diagnosis and needs. It also creates negative outcomes that affect the parents' quality of life and psychological wellbeing [7].

There are still limitations in supporting parents with children with ASD in Malaysia [3]. Parents have brought out several unmet needs when raising their child with ASD in Malaysia compared with other countries such as information, social support, community service, financial support, and family functioning [8], [9]. Parents from different states in Malaysia reported similar situations leading to parental stress and affecting family functioning such as lack of information sharing between healthcare providers and how to access these resources. As a result, parents often feel frustrated and disappointed when they do not receive adequate support from the government and specialists for their disabled children [10], [11]. Due to the lack of accessibility to healthcare and rehabilitation support, trained professionals, and financial constraints, the burden of caring has become the barrier and challenge parents face when raising their ASD in Malaysia [8]. It also affects parents' attitude toward their child's condition which causes a delay in receiving services to build up the child's skills [12]. At the same time, it has affected parents' psychological wellbeing and the capability to advocate for their children to get the services they need [7].

Due to lack of knowledge and support, parents often experience psychological distress and difficulty advocating for their children to others [10], [8]. The previous studies also found that lack of training or professionals to guide them to cope and support children with autism and their families leads to negative attitudes towards their children's condition [4], [11], [13]. Psychoeducation (PE) is an intervention that educates patients on their disorder through systematic, structured, and didactic knowledge. It included explaining the disorder, treatment plan, and prognosis to the patient by providing emotional and motivational support, which would empower the patient to cope with the disorder and improve treatment adherence and efficacy [14], [15]. PE helps parents better understand their children's conditions and available services for their children's condition to deal with the said condition daily [16].

When professionals work with parents, they should be seen as working as partnerships or co-therapists. Through parents' discussion, education and training with professionals might have long-term effects on empowering parents by building up their knowledge and strategies to support their ASD child [17]. Parental knowledge about a disorder indirectly benefits children with autism from the knowledge obtained by their parents [16]. Ebrahimi *et al.* [18] also found out that educating parents have been shown to have the same efficiency as clinician-delivered programs and are a necessary component of support for children with autism. PE has also tested positive results for parents of children with disability, other chronic conditions, and mood disorders [14], [16]. Therefore, the researchers are interested in studying the effect of psychoeducation on the knowledge, attitude, empowerment and psychological well-being of parents with children with ASD.

The problem statement of this study is due to a lack of accessibility to healthcare and rehabilitation support, trained professionals, financial constraints and the burden of caring has become the barriers and challenges parents face when raising their children with autism in Malaysia [8]. It also affects parents' attitude toward their child's condition, which caused a delay in receiving services to build up the child's skills [4], [19], [20]. At the same time, it has affected parents' psychological well-being and ability to advocate for their children to get the services they need [8]. Previous studies found that professional support has helped them better understand their children's condition and cope better with the diagnosis [16]. Therefore, the researchers are interested in studying the effect of psychoeducation on the knowledge, attitude, empowerment, and psychological well-being of parents with children with ASD.

2. METHOD

2.1. Method and design

This study is a true experimental design as the participant will be randomly assigned to intervention or control groups. The independent variable is psychoeducation training with two levels: intervention and control group. The dependent variables of this study are pre and post of knowledge, attitude, psychological wellbeing, and empowerment.

2.1.1. Sample size and location

The study sample size followed the recommendations outlined in Lakens' study [21], demonstrating that true experimental designs with small sample sizes, such as 20 participants, are feasible and supported by existing research. A power analysis example illustrates that a sample size of 20 can be adequate, contingent upon the effect size and power requirements. Specifically, using a one-sample t-test with an assumed true effect size of d=0.5, power computations based on simulations suggest that this sample size provides adequate power to detect the effect.

In this study, the researchers focused on recruiting parents who have children with ASD, who are aged between 2 to 7, and diagnosed with ASD by a psychiatrist, paediatrician or clinical psychologist in Malaysia. The 20 parents had filled up pre and post-session questionnaires. There was one parent in the control group who was excluded due to her son's diagnosis being given by a speech pathologist. There were ten participants in the intervention group and nine in the control group. The parents' ages ranged from 29 to 51 years (the mean age=38; standard deviation=5.82). The gender of the participants was eighteen mothers and one father. In terms of ethnic backgrounds, thirteen of the parents were Chinese, five were Malay, and one was Indian. Parents were located in different regions in Malaysia such as Sarawak, Johor, Penang, Nilai, Ipoh and Klang Valley. The parent's educational background which included one primary school, seven secondary schools, two diploma graduates, six bachelor's degree graduates, two master's levels and one doctorate graduate.

2.2. Instruments

The participants will be requested to sign the consent form and fill in the sociodemographic information. Four questionnaires will be used to assess the parent's knowledge, empowerment, psychological well-being and attitudes towards their children's conditions. The participants will be requested to answer in both pre and post-research within three weeks.

The knowledge and awareness about childhood neurodevelopmental disorders (KACNDD) questionnaire will measure the parent's knowledge about childhood neurodevelopmental disorders [21]. It includes two main domains, which are domain one has six items of CNN's symptoms-related questions. Domain two has eight items related to possible etiologies of CNDDs. The score ranges between 0 to 14. A higher score indicates a higher level of knowledge about childhood neurodevelopmental disorders. Based on Philip *et al.* [21] study, KACNDD questionnaire has good internal consistency with a Cronbach alpha of 0.84.

The family empowerment scale (FES), a 34-item rating scale, was developed to measure empowerment in families with children who have emotional, behavioral, or mental disorders [22], [23]. FBS is designed to measure the empowerment of a parent or caregiver of an emotionally disturbed family member. The FES has three subscales: family, service system, and community. Each item was rated based on a 5-point Likert-type scale (1=not true at all to 5=very true). The higher scores indicated higher empowerment towards family, service system and community. Additionally, FES internal consistency ranges from .87 to .88 across the three subscales, and test-retest reliability correlations range from .77 to .85 [24]. For the convergent validity, FES subscales scores were significantly correlated with patient activation measure (PAM) scores (rFamily=0.60; rService Systems=0.57; rCommunity=0.26), caregiver strain questionnaire-short form (CGSQ; r=-0.28) and strengths and difficulties questionnaire (SDQ) scores (r=-0.35) [24].

Depression anxiety, and stress scale (DASS-21) [25] will measure parents' psychological well-being in this study. It is a 21-item self-reported scale that includes three subscales (depression, stress, and anxiety), with seven items in each sub-scale. Each subscale has seven items with a 4-point Likert scale of 0=Never to 3=Always. Each domain has a different abnormal/at-risk score range, depression (=5), anxiety (=4), and stress (=8). Zhao *et al.* [26] has found that DASS-21 Cronbach's alpha for pre-and post-tests were 0.944 and 0.927 for parents of children with disability.

Parental attitude research instrument (PARI) [27], will be used in this study to measure parent attitudes towards their children with disability. Questions were designed based on five themes of parents' attitudes toward their mental retardation child: love and acceptance, embarrassment, frustration, disappointment, and over-protection. Each item was rated on a 5-point Likert-type scale (A=strongly agree to E=strongly disagree). The parent's responses strongly agreeing with a particular domain will indicate the parent's attitude more towards that theme. Islam *et al.* [28] has used the same scale and found it highly reliable and valid in obtaining information regarding parents' attitudes towards their disabled child.

2.2.1. Online psychoeducation training

The psychoeducation module had been adapted by [3], [29], [30] psychoeducation modules as a reference to create individual psychoeducation sessions, which is more suitable for Malaysian parents who have children with autism. Dr Crendy Tan from the University of Cyberjaya supervised the planning and when conducting the psychoeducation training. The psychoeducation session will be conducted in different languages based on the parent's preference. However, the module was planned based on English. The first session focused on understanding ASD (diagnosis criteria, prognosis, comorbidity, and etiology). The second session focused on the strategies that can apply at home to build up children's social, communication and language and understand children's behavior based on Patra *et al.* [29] study and visual strategies such as Picture Exchange Communication System (PECS), visual schedule, visual task analysis and social story [31]. In the last session, the researcher build parents' advocacy skills following the curriculum by the national family advocacy support and training (FAST) project, a Parent Advocacy Coalition for Educational Right (PACER) center project [32]. It focused on six skills which involved: i) understanding your child's disability, ii) know the key players, iii) know your rights and responsibilities, iv) become well organized, v) use clear and effective communication, and vi) know how to resolve disagreements. Additionally, shared the available services in different regions in Malaysia based on the list of services by Nante [33].

2.3. Procedures

The study received approval in April 2022 from the Ethics Review Board of the Faculty of Social Science and Liberal Arts at UCSI University Malaysia to conduct the study. The Google Form link to sign up for the research will be created. The researchers will share the poster on the Facebook parent's support group page and with early intervention centers and paediatricians to recruit participants. Caregivers who are interested in participating in the research will sign up for the study via the Google Form link on the poster. After receiving the information about signing up, the researchers will email or WhatsApp the participants the Google Form regarding the informed consent form. After receiving the consent, the researcher will email or WhatsApp the participants the Google Form link of the sociodemographic questionnaire, DASS-21, KACNDD, PARI and FES for pre-test data collection. The researcher will randomly allocate the participants into intervention and control groups. Psychoeducation training will be conducted through the Microsoft Teams or ZOOM platform, and the duration of the session will be one hour or one and a half hours. Those who are allocated to the control group will not be given any training.

Once the client has been selected to be in the intervention group, the researcher will contact the participants through WhatsApp to arrange the appointment. They will attend three online psychoeducation training sessions within three weeks. In the first session, participants will learn about ASD, prognosis, comorbidity and etiology. In the second session, the researchers will focus on sharing the home-based strategies (social, communication and language), visual strategies, and behavior management. In the last session, the researcher will wrap up the session by checking if they have any questions. At the same time, share with the parents' advocacy skills following the curriculum by the national family advocacy support and training (FAST) project and provide the list of available services created by Nante [33].

3. RESULTS AND DISCUSSION

Through four independent t-tests, there was no significant difference between the control and intervention groups as shown in Table 1. Then, the four paired sample t-tests were used to measure the differences between pre-and post-training which also found to be no significant differences in knowledge, attitude and psychological wellbeing. However, there was a significant difference between pre and post-session empowerment.

The first independent t-test as shown in Table 1 was conducted to compare knowledge for the intervention and control groups. There was no significant difference in knowledge for the intervention group (M=10.2, SD=3.9) and the control group (M=9.9; SD=3.4; (t (17)=-.186, p=.854). The second independent t-test as presented in Table 1 was conducted to compare the psychological wellbeing of the intervention and control groups. There was no significant difference in psychological wellbeing for the intervention group (M=20.10, SD=12.52) and the control group (M=21.8; SD=19.42; t(13.44)=.221, p=.828). The third independent t-test as shown in Table 1 result showed there was no significant difference in empowerment when compared between the intervention and control group (t(15.45)=.047, p=.96). Even though, the mean and standard deviation of intervention had shown higher (M=126, SD=18.3) than the control group (M=126.44; SD=22.6). Lastly, the independent t-test as shown in Table 1 was conducted to compare the parent's attitudes for the intervention and control groups. There was no significant difference in parent's attitude for the intervention (M=162.7, SD=15.92) and control group (M=173.6; SD=20.96; t(14.9)=1.26, p=.227).

Table 1. T-test result comparing intervention and control group

Variable	Intervention (N=10)		Control (N=9)		*t*	*p*	*df*
	M	SD	M	SD			
Knowledge	10.2	3.9	9.9	3.4	-.186	.854	17
Psychological wellbeing	20.1	12.52	21.8	19.42	.221	.828	13.44
Attitude	162.7	15.92	173.6	20.92	1.26	.227	14.9
Empowerment	126	18.3	126.44	22.6	.047	.96	15.45

The first paired t-test as presented in Table 2 was conducted to evaluate the impact of psychoeducation on parents' scores on knowledge and awareness about childhood neurodevelopmental disorders (KACNDD). There was no significant difference pre (M=165, SD=18.7) and post-session in the intervention group (M=162.7, SD=15.9; t(9)=1, p=.329). The second paired t-test as shown in Table 2 was conducted to evaluate the impact of psychoeducation on parents' scores on DASS. There was no significant difference in the intervention group pre (M=23.8, SD=12.65) and post-sessions (M=20.1, SD=12.52; t(9)=.67, p=.521). The third paired t-test as shown in Table 2 was conducted to evaluate the impact of psychoeducation on parents' scores on PARI. There was no significant difference in the intervention group pre (M=165, SD=18.73) and post-sessions (M=162.7, SD=15.9; t(9)=.536, p=.605). Lastly, paired t-test as presented in Table 2 was conducted to evaluate the impact of psychoeducation on parents' scores on FES. There was significant difference in intervention group pre (M=115.2, SD=13.6) and post-sessions (M=126, SD=18.3; t(9)=-2.5, p=.032).

Table 2. T-test result comparing pre and post-sessions (intervention group)

Variable	Pre session		Post session		*t*	*p*	*df*
	M	SD	M	SD			
Knowledge	10.8	2.9	10.2	3.9	.1	.329	9
Psychological wellbeing	23.8	12.65	20.1	12.52	.67	.521	9
Attitude	165	18.73	162.7	15.9	.536	.605	9
Empowerment	115.2	13.6	126	18.3	-2.5	.032	9

Four independent t-tests were conducted to compare the intervention group, after attending three psychoeducation sessions, with the control group. The results showed no significant differences among parents in the intervention and control groups regarding attitude, empowerment, knowledge, and psychological well-being. Additionally, the paired t-test comparing the results based on pre- and post-session questionnaires found no significance regarding attitude, knowledge, and psychological well-being. However, the pre- and post-session questionnaires showed significant differences in the empowerment scale. This indicates that after the psychoeducation session, the parents feel more empowered and confident in advocating for their children with autism to the community, service providers, and their family members. It is crucial for parents to take on the responsibility of navigating intervention to address autism-related concerns for their children because there is a shortage of access to trained therapists and specialists [34], [35]. "Two-way communication" between parents and health professionals or ASD-related organizations is essential. When parents are involved in the treatment plan, they can pick up the skills to advocate for their children [3]. The advocacy skills help empower parents to understand their child's condition, communicate clearly and effectively, and manage difficult situations when they arise [3], [34].

There were a few factors that might lead to no significant result in this study. Firstly, the years of receiving the diagnosis play a role in the parent's knowledge, psychological well-being attitude, and empowerment. Throughout the years, parents have learned the skills while coping with their children's condition and stress. In the initial stages, parents showed low acceptance of their children's condition. Over 18 months, mothers reported they were slowly adapting, reducing self-blame and accepting their child's diagnosis which was associated with less psychological distress, specifically, less depression and perceived stress. When the parents view the diagnosis as less threatening, it is easier to accept and reduces depression in parents [36].

Secondly, this study included parents from different regions in Malaysia (urban and rural areas) which caused a difference compared to receiving support from professionals. There were parents from the capital of Malaysia, Kuala Lumpur who would be able to receive more professional support compared to parents from urban and rural areas such as Sarawak [3], [37], [38]. There was a lack of ASD service providers in Sarawak and parents were more hesitant due to stigma and "*kampung*" mentality when compared to parents in Kuala Lumpur. Sarawak lacked possibilities for training and professional growth, as well as qualified or experienced personnel in the field of ASD education [39]. A lack of services and professional support causes a delay in early intervention which causes the parents to feel frustrated [9].

Thirdly, the information and format of conducting the psychoeducation session are important. Sarkhel *et al.* [40] also pointed out that psychoeducation should be conducted based on family background and provide suitable levels of information for the family members to understand the client's condition. At the same time, it is an online session, without a physical discussion and home visit which the parents might have difficulty relating to the criteria of their children and understanding the symptoms. In this study, the sharing mainly focused on educating parents about ASD, home-based strategies, and advocacy skills. Therefore, due to a lack of role-playing or practice directly. The parents might have difficulty knowing how to apply the strategies. Previous researches also point out that parent-focused psychoeducational was important for a number of reasons as it focuses on sharing knowledge, information and skills with the parent, which the child with autism is the indirect beneficiary [15], [17], [41]. Additionally, when delivering the session physically which included both lecture and active participation was reported positively by parents. It provided parents with opportunities to share stories and knowledge within the group which helped them explore each other experiences and helped to understand ASD better through mutual support and development of self-efficacy and confidence [42]. Parents also provided positive feedback that by combining individual needs/stories and professional teaching the time is equally shared for education and getting support from others [43].

Forth, participants' attitudes towards the post-session questionnaires. Psychoeducation may just have a short-term effect, as after the parents go back to reality, there are challenges the parents need to face which would affect the result. The participants did not fill up the post-session questionnaires immediately. Most of the intervention group's parents delayed the response for more than two days until researchers sent reminder messages, which may affect the outcome. Filling up the questionnaires would be a burden on respondents as it requires participants to read the questions, recall the information, and fill up the questions which may cause them wanting to answer the questions faster and miss out some of the items [44]. Ergüner-Tekinalp and Akkök [45] also found a similar finding as the quantitative finding did not indicate any difference in mothers' stress levels. However, in the follow-up interviews, mothers shared that they felt more relaxed and had more positive views about themselves and their children [41]. Ilg *et al.* [46] also pointed out that psychoeducation was effective in increasing parents' knowledge of autism and behavioral strategies. However, the increase could be a short-term effect on coping with their children's condition. Although the information is essential to understand the diagnosis better, lack of practice could lead to ineffective behavioral change in the child [14], [15], [46], [47].

Fifth, there were gender differences in attitude towards their child's diagnosis. However, in this study, we only recruited mainly mothers. Previous research found that mothers tend to have a lower level of acceptance, but not fathers. It reported more parental negative feelings and more negative impacts of the child's disability on their social life and marriage. When discussing the experience of learning their child had an illness, males tend to employ a cognitive coping technique while mothers were more likely to adopt an emotional one. Fathers also reported higher levels of marital satisfaction if mothers were able to accept their child's diagnosis. The fathers scored higher on attachment-related avoidance with their children over three years, which means that fathers in the study are less likely to be affected by the changes in children's characteristics, as they were more distant and dismissive [48], [49]. Lastly, this study did not involve the module on stress management and relaxation techniques for parents, which might cause the parents not to develop coping mechanisms to improve their psychological wellbeing. Ilias *et al.* [50] study included guiding parents on stress management and relaxation techniques, which were found to have notably reduced stress and improved psychological wellbeing after they had attended the group psycho-educational programs.

4. CONCLUSION

In conclusion, this study provides insights into the needs and support required by parents while raising and understanding their children with autism in Malaysia. There were no significant differences in control and intervention groups of parents' knowledge, attitudes, empowerment, and psychological well-being. There were also no significant results in pre and post-session in parents' knowledge, attitudes, and psychological well-being. However, the empowerment pre and post-session have shown a significant difference. This indicates that after the psychoeducation session, the parents feel more empowered and confident in advocating for their children with autism. These findings suggest that other interaction factors may affect the effectiveness of psychoeducation sessions in parents' knowledge, psychological wellbeing, attitude, and empowerment. However, there was still a lack of research in creating suitable post-diagnostic psychoeducation for parents who had newly received their children's diagnoses. Future research should continue to focus on this area and should be conducted by using larger sample sizes to get more significant results. They can also investigate the parents' needs and develop a post-diagnostic psychoeducational module based on those needs.

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