

ORIGINAL ARTICLE

Parents' Experiences in Enhancing Self-Help Skills of Children with Autism Spectrum Disorder: A Descriptive Phenomenology Study

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ABSTRACT

Introduction: Children with Autism Spectrum Disorder (ASD) frequently have issues with self-help skills, which make them reliant on their parents. Consequently, parents must develop coping mechanisms and obtain more assistance to feel more supported. However, parents of children with ASD find it challenging to identify the services and support their child's needs and have difficulties accessing them. Thus, this study aimed to explore the parents' experiences in enhancing self-help skills of children with ASD. **Materials and methods:** This study employed a qualitative descriptive phenomenology design using a semi-structured, in-depth interview with eleven parents with children with ASD. All interviews were transcribed verbatim, and the transcripts were thematically analysed. **Results:** Four themes emerged from the analysis: support, intervention techniques, challenges, and satisfaction. Most parents expect formal support includes: information support from the Internet and professionals, practical or advice from experts and parent support groups held by experienced parents or trusted organisations to enhance self-help skills of children with ASD rather than the informal supports (e.g.: emotional, and social supports) they might receive from family relatives or others. Moreover, most parents in Malaysia were unaware of the most recent intervention strategies to teach self-help skills to children with ASD. **Conclusion:** This study contributes to a deeper understanding of the difficulties in looking or waiting for intervention and parents' satisfaction with the diagnosis process and the therapy services they have received in the government and private sectors, which undoubtedly would improve future services to support parents and children with ASD.

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INTRODUCTION

Individuals with ASD often display marked deficits in self-help skills, leaving them unable to complete

basic tasks and have limited potential in educational, vocational, and domestic activities (1). Common self-help skills issues among ASD children discussed in previous studies are toileting skills (2, 3), dressing skills such as tying shoelaces (4, 5) and putting on shirt and pants (6), personal hygiene or grooming skills such as handwashing (7, 8) and brushing teeth (9, 10) and feeding or eating skills (11, 12). It is critical to establish effective and appropriate self-help skills interventions to prevent children with ASD from feeling less valuable

and to lessen the stress and burden on parents. Parents who have children with self-help skill issues experience much burden because their children require more of their time, attention, and energy to teach or assist or carry out or complete the activities (8, 13, 14).

A literature review discovered there are four main types of interventions in developing self-help skills in children with ASD: I) video-based training, II) behavioural in vivo procedures, III) audio-cuing, and IV) social storytelling (15). They also found a trend of studies conducted within the previous ten years on the effectiveness of video modelling (VM) interventions of self-help skills in children with ASD. Parents have a significant role in the overall performance of their children with ASD to reach maximum independence in life and function as the basis or complementary aspect of the therapy process by health professionals, pointing to positive outcomes (16). Considering parents-involvement will be used as the success indicator for high-quality ASD intervention, active participation of parents is encouraged during the intervention sessions (17). Parent-mediated intervention is an approach to better assist parents in building self-help skills for children with ASD through education and training strategies such as instruction, modelling, coaching, or performance feedback with their children at home, which also indirectly improve communication skills and parent-child relationships (18, 19).

Parents of children with ASD must overcome various obstacles to improve their children's self-help skills. These obstacles include finding or identifying appropriate treatment such as parenting skill training, educational training programs for their children and other services, and knowing where to find and access them, which makes it difficult for them to find the time and money to pay for these services (20, 21). Several studies have explored experiences and looked at the difficulties and challenges of parents with ASD children in Malaysia so far to reduce parental stress and improve the quality of life of their children or adolescents with ASD and overall family mental well-being (17, 22–26). However, none of the studies focused on the parents' experiences and involvement in enhancing and maintaining self-help skills of children with ASD in the Malaysian context. Thus, this study intended to explore the parents' experiences in enhancing self-help skills of children with ASD, which may inform future services and management for children with ASD in Malaysia.

MATERIALS AND METHODS

Study design

A descriptive phenomenology design was employed to explore parents' experiences in enhancing self-help skills of children with ASD. Descriptive phenomenology design aims to understand human phenomena by analysing the meaning of lived experiences and organising data in a meaningful way (27). A total of eleven

participants consented and agreed to be interviewed. All parents were interviewed regarding their experiences using the right strategies to improve self-help skills of their children with ASD. Purposive sampling was used to recruit the eligible participants: (i) parents of children diagnosed with ASD aged from 3 to 9 years old, (ii) able to understand and communicate either in English or Malay, and (iii) agreed to be interviewed. The participants were excluded if they had cognitive or neurological problems hindering their ability to understand and respond to the questions. This study was approved by the Research Ethics Committee of the Universiti of Technology MARA: REC/11/2021 (MR/847). To protect the confidentiality of the participants, the individualised participant's code was used.

Materials and data collection procedure

Data were gathered through semi-structured in-depth interviews that consisted of open-ended questions related to parents' experiences in improving self-help skills of their ASD children. The interview guide was used during the interview, and prompt questions were asked to get rich and complete data from the participants. The interview questions are derived from the literature review and are based on the ontological and epistemological of lifeworld forms (27). A pilot interview was conducted to test the interview guide and its flow and to match the study's content and concepts. For instance, the participants were "Could you describe how you train your child to be independent in daily living activities, i.e. dressing in upper and lower garments?" All interviews were digitally recorded with participants' permission and transcribed verbatim before the analysis. The interview was conducted at the participants' preferred location, time and duration (ranging from 30 to 60 minutes) to ensure maximum information about the participants' experience was obtained. Before the interview, participants were given information about the study and the consent form. The richness of the data was achieved after the last participant was interviewed.

Data analysis

Data were analysed using thematic analysis as described by Sandler et al., (27). Thematic analysis based on a descriptive phenomenological technique moves from the raw data to discover meanings, organise into patterns, and develop themes connected to the study's goal and setting (27). The following steps were used in the analysis process: I) familiarise the transcript and data through open-minded reading, II) search for meaning and themes using manual coding, and III) organise themes into a meaningful wholeness. Throughout the research process, transcripts were peer-reviewed, and all processes were documented clearly. The study's rigour was ensured through reflexivity, credibility, and transferability (27). Reflexivity was done by comparing the original data with the descriptive text of themes to minimise the researchers' influence in the analysis process. Credibility was ensured through member

checking with three participants, and any changes to the themes, subthemes and codes were discussed with the research team until a consensus was achieved. Finally, transferability was ensured by providing a rich and thick description of the research process and the study's context.

RESULTS

Participants' Description

Thirteen participants were approached, but only eleven replied and agreed to participate in the study. The age of the participants ranged from 28 to 36 years. Meanwhile, the age of their children with ASD is between three and six years old and all of them are boys. All the children were diagnosed with mild to moderate ASD. Most of the children receive treatment from government hospitals as well as private agencies. Table I shows the participants' descriptions in this study.

Four major themes about parents' experiences in enhancing self-help skills of children with ASD, namely supports, intervention techniques, challenges, and satisfaction. Figure 1 shows the emergent themes from the analysis of the data.

Theme 1: Supports

This theme explains the support and assistance needed by parents of children with ASD in improving self-help skills such as wearing clothes, using the toilet, eating and others. Three subthemes are information support, practical and guidance from professionals and social support groups for parents of children with ASD. All parents desperately need information related to ASD that is accurate and appropriate to their child's current condition and age. Among the sources of information related to ASD received are from the Internet or social media and professional experts. "I have difficulty getting information from experts, it requires so much time to find information that is accurate and appropriate for my child's situation" [P1].

Most parents agreed that practical guidance from professionals such as developmental paediatricians,

occupational therapists, speech therapists, and experienced parents is important in improving children's self-help skills. Among the forms of practical guidance needed are workshops, webinars, and parenting training programs specifically for parents of children with ASD. "It is essential to follow a training program for parents of ASD children because we will get 'parenting skills' with more details, and we as parents need to learn the right way to educate them" [P4].

Participants also mentioned parent-support groups. This type of support can help parents deal with the stress and challenges of managing their children and helps in sharing information, experiences, and skills in teaching self-help and communication skills while waiting in line for intervention sessions and waiting for appointments with specialists. "I look for a 'support group' for parents of ASD children because there is much information that can be shared based on parents' experience and advertisement about talk programs or webinars organised by the therapist or developmental paediatricians" [P1]. Another parent also stated, "Most of the information I got from my friends who have an autistic child...either on diagnostic procedure or intervention program" [P11].

Theme 2: Intervention techniques

The second theme refers to intervention methods to improve children's self-help skills. Prescribed intervention techniques include VM, verbal prompting, physical prompting and demonstration and mixed

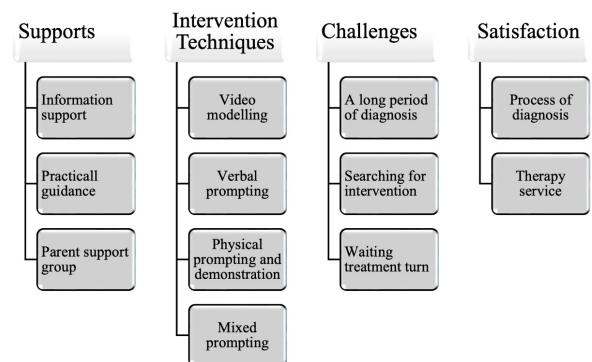


Fig. 1: Emergent themes and subthemes from the data analysis

Table I: Description of participants in the study

Code	Age (P)	Sex (P)	Age (C)	Sex (C)	ASD Specified Level	Educational-Level	Occupational Sector	Income Class
P1	36	F	5	M	Mild	Uni/Col	Government	M40
P2	31	F	3	M	Mild	Uni/Col	Private	M40
P3	29	M	4	M	Mild	Uni/Col	Private	M40
P4	30	M	3	M	Mild	Uni/Col	Government	B40
P5	31	F	4	M	Mild	Uni/Col	Housewife	B40
P6	31	F	6	M	Moderate	Uni/Col	Housewife	B40
P7	28	F	6	M	Moderate	Uni/Col	Housewife	B40
P8	30	F	6	M	Mild	Uni/Col	Government	B40
P9	35	F	5	M	Mild	Uni/Col	Housewife	M40
P10	29	F	6	M	Moderate	Uni/Col	Private	M40
P11	28	M	6	M	Moderate	Uni/Col	Housewife	M40

Note: (P)-Parent, (C)-Child, F-Female, M-Male, Uni/Col-University/College (tertiary education), B40- Bottom 40%, M40-Middle 40%

prompting as subthemes under this theme. Most parents know that the VM method can be done with children with ASD while teaching self-help skills but have never used it. "I have heard of VM before, and my son has done activities to watch videos and imitate the action in it with a speech therapist by learning to dance to the song 'Head, Shoulders, Knees & Toes'. I never tried it to improve self-help skills" [P3].

Most parents are taught to provide verbal prompting by giving clear, simple, and concise verbal instructions to make it easier for their children to understand and master specific skills such as using the toilet, dressing, and brushing their teeth. "We always watch over him when he is in the toilet. We give simple instructions if he forgets to do something such as pump the toilet after use or wash his hands before coming out of the toilet." [P2].

Several parents use full or partial physical prompts and demonstration methods in teaching daily activities and mastering self-help skills to their children with ASD. "My son has trouble eating foods like rice, my husband showed him how to eat using a spoon while feeding my second child so that he will imitate the action" [P1].

The fourth subtheme, 'Mixed prompting' emerged from the analysis as it covers all types of prompts that the parents may combine to teach their children to improve self-help skills. Most of the time, parents indirectly use various types of prompts, which is hard to categorise, as children who need physical or gestural prompts indirectly will obtain verbal instruction and audio prompts, or some of them need visual prompts. "My child tends to use both hands when he eats using a spoon. So, we will continuously tell him or sometimes point to his right hand to switch the spoon back" [P6].

Theme 3: Challenges

The third theme from the direct excerpts of the participants' interviews was challenges, including a long diagnosis period, seeking appropriate interventions, and waiting for treatment turn. The diagnosis period is one of the first challenges parents face in determining whether their child has ASD. The waiting process requires much patience and can cause parental anxiety. Most parents received a diagnosis from a specialist doctor for more than six months. "I made an appointment to meet with a child psychiatrist. My appointment with the specialist has taken a long time. I had waited for the diagnosis from a government hospital for 6-8 months. I could not wait any longer; I made an appointment at a private hospital to receive the diagnosis" [P1]. This theme could be further exemplified by "My child was initially seen by a family medicine doctor, and the impression was speech delay. I waited for many years to see a paediatric specialist, and finally, my child was diagnosed with autism after a few years of waiting the turn with a paediatric specialist" [P11].

The process of finding the right and appropriate treatment or intervention for children with ASD poses a challenge to parents if they are not helped or guided by health professionals until their children are referred for treatment to occupational therapists (OT) and speech-language therapists (SLT) in the hospital, centre, and locum, especially for parents that live in rural areas. "My child has followed up with OT in the hospital once every three months while for SLT once every six months. But I feel very disappointed as in my living area, there is no centre and very difficult to find a locum therapist which I can send my child for every weekly session" [P9].

Ensuring their children behaved well while waiting for treatment turns was challenging for parents. "My son was crying during the session, the OT felt like my son didn't want to cooperate well and suggested ending the session and asked me to come next time, which I had to wait for the next 1-2 months" [P2].

Theme 4: Satisfaction

The last theme refers to the satisfaction of the parents with several things, including the diagnosis process and the treatment or services provided by the therapists. Parents felt unhappy with the long diagnosis period. "I felt frustrated as I waited to get my son's diagnosis. After six months of waiting, I took the initiative to meet with a child psychiatrist at a private hospital to get the diagnosis" [P1].

In the government sector, some parents feel that the treatment or services provided by occupational therapists in hospitals are limited. Some parents felt unhappy for not being fully helped with limited sessions. However, few parents shared their satisfaction with the therapist's expertise and professionalism in the public hospital who takes other initiatives in helping her to improve their sons' overall performances. "As I live in a small town, which is far from the urban area, there is no centre here for me to send my child... I am grateful as the OT in the hospital was very responsible as she knew about the parents' limited resources. She asked me to send a video about my son performing activities she suggested to do at home and then gave me her feedback" [P8]. Next, most parents that send their children to private centres are delighted with the treatment and services provided. "They (therapists) continue advising outside the session time. There is a difference between private and government services. We upload our son's activities at home, and when the OT looks, he often advises what we need to add to further improve his performance" [P3].

DISCUSSION

This study aims to explore the parents' experiences in improving self-help skills of children with ASD. Findings indicated that most parents expressed their desire for informative assistance, practical guidance,

and parent-support groups to ensure their children with ASD receive appropriate therapies to enhance their self-help skills. The current study found that all parents preferred formal informational support by means they demand knowledge from professionals and experts such as doctors, therapists, and other related health professionals to improve self-help skills of their children with ASD. Parents believe in the importance of having experts to enhance their knowledge (28). Furthermore, attending the parent education and training programme is important since it gives both knowledge and parenting skills in greater depth, allowing parents to understand how to improve their children's self-help skills properly. The program allows the information or skills to be passed on to parents using a variety of methods, such as discussion either online or face-to-face timing and video guidance in a setting where parents and professional facilitators are the direct participants (29, 30). Similar to a previous study (31), the parent requires more parent-support groups to connect with other parents who face similar issues, to assist them in receiving formal information or plausible resources, and to help other parents while being supported.

Most parents use various strategies to enhance self-help skills of children with ASD, including prompting, demonstration, and modelling. This is supported by research on the effectiveness of verbal prompting for teaching hand washing and teeth brushing skills to students with ASD in school (8). Physical prompts with rules and reinforcement to teach children with ASD to raise their hands resulted in them learning accurate hand-raising skills in response to progressively more challenging tasks during group instruction (32). Participants rarely used VM. However, most of them showed interest in knowing more and used this method with their children in the future. This is because they have never been introduced to this technique by professionals or experts. This is understandable because there are no local studies that cover VM in any intervention for children with ASD or even for children with general mental problems, implying that our local practitioners have not adopted the treatment strategy yet (33).

The hurdles experienced by parents of children with ASD include waiting for one's turn to receive treatment, a long period of diagnosis, and finding the best intervention or therapy. For accurate diagnosis of ASD, thorough, in-depth interviews and histories are required, which may result in a long process of ASD diagnosis (34). In addition, the lack of facilities to accommodate the growing number of children diagnosed with ASD in rural regions contributes to extended wait times for intervention appointments at government hospitals (35). In Malaysia, parents who sought care for their children in public hospitals confronted a separate difficulty in the form of significant wait times for intervention (17).

The divergence of findings in satisfaction during the

diagnosis process and therapy services was observed in this study. Some parents received very late diagnoses and incorrect diagnoses. Meanwhile, some parents obtained sufficient information from the paediatricians throughout the diagnostic stage. Parents who were given information on ASD, how it may affect their children, and where they may get treatment or intervention and related supports were more satisfied with the medical care (36). Parents who received therapy services in the government sector were less satisfied due to inadequate treatment and limited sessions compared to services they received from the private sector. This is due to the shortage number of therapists in Malaysian government hospitals. However, parents are grateful if therapists offer alternative ways to assist them in improving their children's overall performance, such as giving them feedback and answering their inquiries via text or calling out the treatment session. Every client requires adequate responses, but therapists in public hospitals in Malaysia already have a schedule filled with clients, causing it challenging to implement telehealth and parent-mediated intervention (17, 37).

A greater comprehension of the challenges, supports, and resources experienced by parents of children with ASD was provided by this study, which would enhance services for children with ASD and their families. Furthermore, this study informs the necessity of developing standard parent-mediated intervention programs in the future, particularly for parents of children with ASD in Malaysia. These programmes have vital roles in helping and guiding parents to manage and handle children with ASD in communicating and navigating daily life for independent living. It may also indirectly lower the parental stress by giving them the exact support they need for their children to master the acquired skills.

The homogeneity of the samples, including the fact that all participants were Malay parents, was the study's weakness, which could not be transferable to other races in Malaysia. Although all the participants' financial information was gathered before the interview session, it needed to be comprehensively analysed, given that previous research has shown that a family's socioeconomic status can allow or prevent better access to services and support. For example, families in Malaysia with household income statuses that fall into the B40 category may struggle to pay for a daily or weekly intervention from private centres.

CONCLUSION

This study suggests that most participants expected proper support, which includes three types of support: information support, practical guidance from experts and parent support groups held by experienced parents of children with ASD or trusted organisations. Parents of children with ASD use various intervention strategies

and look forward to using a new strategy, including VM to improve the self-help skills of their children. This study offers perspective on the parents' needs to access additional and better support for their children with ASD and themselves as parents. The similarity in the intervention techniques, challenges and satisfactions found both in this study and the literature help to add credence to the shared similarity of needs amongst parents who have children with ASD. This study highlights the need of parent-mediated intervention to support the parents in enhancing the self-help skills of children with ASD.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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