

The Therapist's Perspective of Parental Involvement in Applied Behavioural Analysis (ABA) Therapy for Children with Autism Spectrum Disorder (ASD)

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ABA interventions have been widely known as the most effective evidence-based interventions for children with ASD. Parents have been reported as a critical component that impacts ABA treatment outcomes in the long term. However, many parents still do not partake in ABA treatment as recommended or end up dropping out before behavioural issues are resolved. This study aims to understand ABA therapists' perception on parental involvement, perceived level of involvement, and factors leading to involvement. Five ABA therapists in Malaysia were recruited for the purpose of this study. A semi-structured interview method was used, and thematic analysis was utilized to code the data. The themes identified for perceived parental involvement include active interaction between parents and therapist, engagement with the ASD child, behavioural observation of the ASD child, commitment to attend ABA parent training, compliance with the ABA teaching at home, and adjustment of parental behaviours that interferes with therapy. Differing perceptions on the level of parental involvement were found. Parental stress level, involvement from fathers, parents' career, ASD severity level, parents' efficacy and accessibility to a therapist are factors perceived to be related to parental involvement. A greater focus on how to improve parental involvement could be beneficial for the therapist, parents, and the child him/herself.

Keywords: parental involvement, ABA, therapist, autism, ASD

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition where the affected person faces challenges in their social skills, portrays rigidity/repetitive behaviours, and has difficulty in speech and nonverbal communication (American Psychiatric

Association, 2013). ASD is also a term recognized globally that signifies a wide spectrum of social cognitive delays, and it is usually diagnosed within the first 2 years of life but persists across a lifetime. According to the Diagnostic and Statistical Manual of

Mental Disorders Fifth Edition (DSM-5), ASD is diagnosed when the child is having difficulties in two areas: social communication and restricted, repetitive behaviour.

Applied Behavioural Analysis (ABA) is a science-based method that focuses on the relationship between a person's environment and behaviour (Kacurovski, 2009). "Behaviour" refers to actions and skills of sorts instead of just actions that are considered misbehaviours, whereas "environment" refers to surrounding events that may be changed by the behaviour (Autism Speaks, 2018). ABA uses behavioural principles such as positive reinforcement and understanding behavioural antecedents and consequences in order to build desired skills and behaviours in children (Autism Speaks, 2018). Services based in ABA are the most widely used evidence-based practice for children with ASD (Peters-Scheffer et al., 2011). 90.8% of parents that participated in a study perceived that ABA therapy is beneficial to their child (Becerra et al., 2017).

Parental involvement has shown critical influence on long-term ABA treatment outcomes, as parents could provide important information on the child, and the skills learned during treatment sessions could be applied and generalized to the home setting (Burrell & Borrego, 2012). Although parental involvement is a very important component during different stages of treatment and development when it comes to children with ASD (Azeem et al., 2016), a lot of parents still do not partake in ABA intervention as recommended or parents end up dropping out before the behavioural

issues are resolved (Matson et al., 2009).

Research over the past 30 years has provided support on the importance of getting parents empowered and adequately trained to implement ABA interventions (Dunst, 1985; Dunst et al., 2000). Parents are capable to learn and implement ABA techniques on their children (Subramaniam et al., 2016). Interestingly, parental compliance to intensive behavioural treatment such as ABA has been the lowest compared to other therapies such as speech-language, occupational therapy, or even dietary interventions (Shepherd et al., 2018). Moreover, Hock et al. (2015), found compliance to behavioural treatment is lower compared to medication or developmental treatments. This may be due to cultural factors. ABA originated from the United States, where parental involvement in treatment is a norm. It would be helpful to explore if parental involvement in therapy is due to cultural factors, as suggested by Teo and Lau in a Sarawakian study (2018).

Since parental involvement is a variable that affects the efficacy of ABA treatment, it is vital to explore ABA therapists' perception on parental involvement, parents' level of involvement, and factors leading to involvement for children with ASD. Therefore, this study has the following research objectives:

1. To understand ABA therapists' perception of parental involvement of children with ASD
2. To explore ABA therapists' perception on factors leading to parental involvement.

Method

Participants

Purposive sampling was used in this research to recruit participants that have experience with the research topic. Five ABA therapists were recruited. Table 1 portrays the demographic information of the participants.

Table 1
Demographic information of the respondents

ID	Age range	Years as a therapist
1	35-40	14
2	30-35	9
3	25-30	5
4	20-25	2
5	35-40	12

Measures

The Parent Involvement Questionnaire: Measuring Parents’ Involvement in Behavioural Intervention for their Children with an Autism Spectrum Disorder by Solish et al. (2015) was used to construct the interview schedule. The following questions were asked while probing was used to elicit deeper answers from the participants:

Research question 1:

1. What is your perception of parental involvement?
2. What kind of behaviours come to mind when parental involvement is mentioned?
3. Please elaborate on some examples of parental involvement.

Research Question 2:

1. What are your perceptions of factors that impact parental involvement?

2. In your opinion, what factors can lead to increased parental involvement?
3. What do you think are triggers that can cause parents to shy away from being involved?

Procedures

Participants were recruited through a website search on ABA therapists in Malaysia. Identified participants were approached by email or telephone to ensure criteria to be included as research participants were met. Thereafter, an appointment was made for the first interview session. Written consent was obtained from the participant prior to the interview session. An interview session was conducted face to face or virtually. A second interview session date was also made for the follow up session.

Once the interview sessions were completed, data obtained from the interviews were coded and analysed. The narrative thematic analysis process that was used in this research consisted of five steps: (1) organization and preparation of the data (2) obtaining a general sense of the information (3) coding (4) categories or themes (5) interpretation of the data (Creswell, 2014).

Results

The coding of the first research question generated 6 themes and the second research question generated another 6 themes (Table 1).

Table 2
Summary of themes from the findings of the study

Therapist’s perceptions on the definition of parental involvement in treatment
<ol style="list-style-type: none"> 1. Active interactions between parents and therapist 2. Parents’ engagement with the child 3. Parents’ observation of the child’s behaviour 4. Commitment to attend ABA parent training 5. Complying with ABA teaching at home 6. Change parental behaviours that interfere with therapy
Factors relevant to parental involvement
<ol style="list-style-type: none"> 1. Stress 2. Involvement from fathers 3. Parents’ career and level of career 4. Severity level of ASD 5. Parent’s efficacy 6. Accessibility to therapist

The first research question aimed to explore an ABA therapist’s perception on the meaning of parental involvement when treating children with ASD.

Theme 1: Active interactions between parents and therapist

Active communication between the parents and therapist seems to be what all respondents (n=5) resonated with when asked about the perception of parental involvement.

“Therapy is also a partnership between therapist and the parents. There should be constant communication for the therapist to share progress and parents to feedback observation” (Respondent 1)

The respondents went on to say that involvement means having parents frequently feedback on the child’s

condition and behaviour at home so that therapists are well-informed and are able to plan upcoming sessions according to the child’s progress. This was perceived as important because parents were the closest person to the child.

Theme 2: Parents’ engagement with the child

All respondents (n=5) mentioned that being engaged with the child defines involvement. Interaction can be in the way of communication, play, spending time practicing skills or just being present with the child.

“Interaction! ASD child interacts very differently... parents need to take time to understand how their child prefers to interact, could be a conversation, play, spend time... and do that with the child” (Respondent 2)

One respondent pointed out that an ASD child needs attention, an involved parent must always spend time to engage whichever way the children prefer especially if they are non-verbal.

“Engage with the child... talk to the child, be there with them, communicate with them...ASD child needs the attention especially if they are non-verbal” (Respondent 4)

Theme 3: Parents’ observation of child’s behaviour

Most respondents (n=4) perceived that observing the child’s behaviour out of therapy is an important involvement from parents.

“Always take note of what is needed to be done, really take time and effort to observe.... Whenever a therapist asks a question about the child, the parents must be able to

accurately answer... Especially about their life habits at home i.e., sleep, eat, behaviors... such information is highly vital for therapy” (Respondent 4)

The respondents (n=3) went on to say that observation of the therapy sessions and taking notes is also perceived as a type of parental involvement. The reason is mainly for parents to understand what is being taught to the child and learn some of those skills.

Theme 4: Commitment to attend ABA parent training

Some respondents (n=3) perceived involvement as parents making time to attend parent training religiously and following instructions on ways to manage the child’s behaviour.

“Involvement to me means that parents should commit themselves to be heavily involved in the parent training...” (Respondent 5)

Theme 5: Complying with ABA teaching at home

All therapists (n=5) mentioned that involvement means having parents comply in applying the ABA teaching or techniques at home. Parents should perform generalisation skills at home to convert the skills that the child has learned into a common behaviour.

“When spending time with the child, parents have to perform generalisation skills... so that the skills that the child learn can become a common behaviour. Parents must also understand how to generalise at home creatively.... to make the child engaged at home...” (Respondent 1)

Respondents went on to explain that when parents comply with the teaching, they are creating a consistent

environment that avoids confusion, regression and helps the child to progress faster in therapy.

“Create a consistent environment for the child so that he or she is not confused... avoid confusing them with inconsistent treatment, for example, sometimes a behaviour is being reinforced, sometimes it is not.” (Respondent 5)

Theme 6: Change parental behaviours that interfere with therapy

Some respondents (n=2) define involvement as parents changing behaviours that interferes with therapy in front of the child at home to prevent difficult behaviours from happening. This may require a bit of planning for the parents, but it is important to the child that is going through therapy.

“Parents must try their best and even change certain things or behaviours at home to prevent a behaviour from happening... We teach parents how to do that... and this requires a lot of planning and thinking.” (Respondent 5).

Research question 2 aimed to explore the therapist’s perception on factors that relates to parental involvement.

Theme 1: Stress

Most of the respondents (n=3) perceived that stress affects parental involvement.

“Stress! The feeling of helpless and hopelessness. Having a challenging behaviour at home and not being to manage it is stressful so they just give up...” (Respondent 2)

The same respondent went on to explain that worrying about an ASD child's future brings about stress to the parents.

"Thinking about an ASD child's future can be stressful; the uncertainties, triggers... really stresses the parents" (Respondent 2)

Theme 2: Involvement from fathers

Involvement from fathers was perceived by respondents (n=2) as one of the factors leading to parental involvement.

"...most of the time we see only mommy... having daddy along to learn how to manage the child's behaviour and support the child at home is important" (Respondent 3)

It was explained that when both parents are involved and understand the child's progress, there is mutual support and motivation between the parents to continue their commitment and involvement.

"Mommy needs support and daddy should be in this together... this way, they motivate each other through tough times..." (Respondent 4)

Theme 3: Parents' career and level of career

Almost all respondent (n=4) perceived parent's careers as one of the important precursors leading to parental involvement.

"Working mothers have difficulty participating in the parent training due to work commitments and their busy schedule. This usually causes them to be extremely exhausted after work to be able to really spend quality time with their child" (Respondent 3)

Three of the respondents went on to relate that career level also makes a difference.

"Time is a constant challenge... especially when parents are CEOs and Directors of a company. They don't have time participate..., or to understand their child's progress" (Respondent 5)

"Parents just have no time. The higher their career position, involvement becomes lesser" (Respondent 1)

Theme 4: Severity level

Most of the respondents (n=3) perceived that there are differences in parental involvement when a child is diagnosed with a different level of ASD. However, differing patterns of involvement were described by the therapists.

One respondent perceived those parents of a child with ASD Level 2 tend to be the most involved because parents of level 2 ASD child has high hopes that the child can improve to Level 1 and eventually become a typical child. Next in line will be parents with Level 1 ASD children, they are also very involved because they too have a strong desire and hope that the child can be treated and is able to attend a normal school like a typical child. Parents tend to be more involved because the behaviours of a level 1 ASD child is more manageable.

"Level 1 parents are involved because the child is easier to manage... They have a goal to see the child become typical...Level 2 parents are the highest because they perceived that there is a high chance for their child to improve to Level 1 and if they see improvement, they will be more"

involved to support the child and hope that one day the child becomes a typical child.” (Respondent 1)

Another respondent perceived a similar pattern, where are more involved when the child is not so severe because the behaviours tend to be more manageable.

“In my opinion, parents are more participative when the child is more settled down... Settled down meaning minimal behaviours and can respond to instructions” (Respondent 5)

However, another respondent has a very differing perception. It was perceived that parents are more involved when the child is higher on the spectrum. This is because parents realise that the child would need more support compared to those not so severe hence involvement gets lesser when the child moves down the spectrum.

“Parents are even lesser involved when the child is highly functional because they tend to be more independent... When the child is severe, parents tend to pay more attention” (Respondent 4)

Two of the respondents perceived that the severity level of the child does not affect parental involvement. It was perceived that the motivation and commitment of a parent will not change regardless of the child’s severity.

“When a child is diagnosed with ASD, regardless of severity, it is a big thing to all parents... So, if they are the kind that will get involved, they will, if they are the kind that doesn’t, they won’t.” (Respondent 2)

Theme 5: Parent’s efficacy

Almost all respondents (n=4) perceived that parents’ ability to interact and manage the child’s behaviour affects their involvement. The lack of knowledge makes it difficult for parents to manage challenging behaviours at home. When the behaviour gets worse, and parents do not have the knowledge to manage the situation, it further demotivates the parents.

“Parents don’t know how to communicate with the child...especially an autistic child may interact very differently from a typical child...They then see a different child at home compared to when they are in therapy, and this totally demotivates them to follow through with future interactions” (Respondent 4)

A few respondents went on to explain that helping parents to be successful at managing child’s behaviour at home could help increase their involvement.

“Setting the parents up for success. As therapists, we get parents to be involved with an easier task so that when they succeed, they are reinforced to carry on... the more successful they are, the more motivated they are to remain on the bandwagon” (Respondent 5)

Theme 6: Accessibility to therapists

One respondent perceived easy access to the child’s therapist itself could affect parental involvement. And ideally, this should not incur additional costs to the parents. Many times, parents are not sure how to support their child when the behaviour happens, and they need immediate guidance. If support was available, parents would feel more confident and continue to increase their involvement.

“Open access to therapist... Access that does not require an extra fee for parents to speak with therapist... could be Whatsapp, e-mail, Zoom... it does not matter.” (Respondent 1).

Discussion

This study found that therapists' understanding of what parental involvement means could be very diverse. Active interaction between parents and therapists was perceived as one of the main definitions of parental involvement in this study. It was perceived that parents, being the closest kin to the child, should be responsible to share a detailed observation with the therapist in order for the therapist to plan therapy accordingly. Indeed no one knows the child better than the parent, hence the insightful information provided will contribute to the outcomes of the ABA program (Baruah, 2013).

Being engaged with the child is perceived as a way of involvement in this study. This is consistent with Kuhn and Carter's (2006) broad definition where he states that parents of ASD children can be involved by engaging in interaction with the child. Engagement can be in the way of communication, play, spending time, practising skills or just being present with the child. Engagement and time spent with the child are also important because those moments can be converted to teaching opportunities reflecting important family values and routines, and at the same time bring out the child's strengths and preferences (Buschbacher et al., 2004).

In this research, it is found that observation of a child's behaviour during therapy and at home is perceived as a type of parental involvement. This

finding is consistent with Solish and colleagues' (2015) definition that called out parents' observation during therapy as parental involvement. However, Solish et al. (2015), did not mention parents' observation at home as a type of involvement. According to Baruah (2013), parents can track a child's antecedent, behaviour, consequences (ABC) data at home and in the community.

Commitment to attend parent training and abide by the instructions to manage ASD child's behaviour is perceived as a definition of involvement in this research. Similarly, Nock and Ferriter (2005) refer to parental involvement as regular attendance during interventions focused on parents. When parents commit, they will be able to provide the child with learning opportunities outside of therapy and this is able to support the child in building skills and generalisation (Kasari et al., 2015).

Decades of research has shown the importance of parents being trained and empowered with the right skills to implement an intervention. (Dunst, 1985; Dunst et al., 2000). Furthermore, techniques of ABA can be learned and implemented by parents (Heitzman-Powell et al., 2014; Subramaniam et al., 2016; Wainer & Ingersoll, 2012).

Findings from this research indicate that parental compliance in applying ABA teaching at home is perceived as parental involvement. Parental commitment to attend training was highlighted, but Nock and Ferriter (2005) also refers to parental involvement as an implementation of treatment strategies in between therapy sessions. Parents should be able to continue to the ABA techniques in daily activities because this is an essential component of the therapy (Baruah, 2013). In many cases, parents are often

able to learn the skills but may not effectively use them after learning it (Moore & Symons, 2011).

The last perceived definition that surfaced from this research was parental behaviours that interfere with therapy. This point was not mentioned in the definition in previous research. A common feature of most evidence-based practices for disruptive behaviour problems is for parents to support the change the child is making by changing parenting behaviours (Eyberg et al. 2008; Garland et al., 2008). A child's disruptive behaviors could stem from inconsistent or poor parenting skills. Therefore, parental involvement in ABA therapy could indirectly teach the parents to model desired behaviours to their children and be more consistent in implementing rewards or consequences to their children.

Therapists perceived stress as one of the factors leading to lower parental involvement. This finding is consistent with other studies that shows parents of children with ASD demonstrates a higher level of stress compared to other parents who have typical children or even those with other disabilities (Benson, 2010) In a study conducted by Nikmat et al. (2008) in Malaysia, it was found that 53.8% of parents of children with autism showed a clinical disturbance in psychological wellbeing, conceptualized as clinically elevated scores on the General Health Questionnaire (GHQ-28), and 90.4% of parents demonstrated significant parenting stress. When parents are stressed, they are perceived to have poorer communication with their children (Osborne & Reed, 2010).

Findings from this research suggest that stressors such as work, marital, severity level of the child and worry about the uncertainties of the child's future are

factors that affect parental involvement. This is consistent with past research that shows the severity of ASD symptoms in a child being a common source of parental stress (McStay et al., 2013). Concerns about the limited access to ASD therapy (Vohra et al., 2014) and additional life demands such as financial burdens and constrained employment opportunities (Dardas & Ahmad, 2014) are other common stressors that elevate parental stress, leading to lower involvement (Osborne & Reed, 2010).

This research also found that involvement from fathers was one of the factors that lead to parental involvement. Respondents of this research indicated that with fathers' involvement, parents can mutually support each other. It is common that mothers are the ones identified as the primary caregivers to children in the family (Dardas & Ahmad, 2014; Foody et al., 2015). The focus of most research is primarily on understanding mothers, giving little attention to understanding fathers' involvement (Hu et al., 2019).

Evidence is showing that fathers of children with ASD plays a unique and important role in maintaining the overall wellbeing in the family (Flippin & Crais, 2011; Lashewicz et al., 2019; Rankin et al., 2019). Not only that, but their involvement in childcare also correlates with lower parenting stress and greater marital satisfaction in the family (May et al., 2015; Thullen & Bonsall, 2017). These findings support the findings from this research that the father's involvement is a factor that affects parental involvement in the family.

This study found that a parent's career is perceived to affect parental involvement. This is consistent with findings from previous research that

indicates that due to the high cost of therapy, parents have a commitment to continue working and this does have an impact on the amount of time parents have to spend with their children (Teo & Lau, 2018). In addition to career, findings also suggest that parents with a higher occupational status spent less time with their children. As most of the primary caregivers were mothers, women with a higher career status may be more likely to work full time, experience more stress, or place their children in the care of others (such as daycare).

The severity level of the child with ASD is perceived to be a factor leading to parental involvement in this research. However, differing patterns of involvement were correlated to the severity level. Some respondents indicated parents are more involved when the severity level is lower while some respondents perceived parents being more involved when severity level is higher. Past research has shown that the severity level in the ASD child was a major variable that can be significantly correlated with parental involvement. Parents perceived the need for greater involvement when they see more behaviour problems in their children (Schlagel, et al., 2012). Brookman-Frazer et al. (2010) also suggested that higher severity and complexity is associated with higher involvement.

This research revealed that parents' ability to interact and manage the child's behaviour is perceived as a factor leading to parental involvement. When parents fail to communicate and manage challenging behaviours at home, it derails them from involvement. The findings are consistent with past research that shows over 90% of parents who have children with ASD, have challenges dealing with behaviours and

this is causing anxiety for the parents (Bitsika & Sharpley, 2004). It reflects the effect parent efficacy has on parents' stress level that is perceived to affect the level of parental involvement.

Respondents in this research suggested that starting parents with easier tasks coupled with adequate training will encourage involvement (LeFrançois, 2012). The parent self-efficacy relationship found in past research has suggested that parents who are more confident in providing interventions are more likely to repeat those behaviours (Solish & Perry, 2008). Hence, coming up with strategies such as starting small for the parents can help them to be more motivated to be involved in treatment. From this perspective, parent training programs can support parents in increasing self-efficacy (Clancy, 2017).

Having accessibility to the therapist for advice and support is perceived as a factor leading to involvement. Many times, parents are not sure how to support their child when the behaviour happens, and they need immediate guidance. Having access to the therapist would increase self-efficacy, and naturally that would lead to parents wanting to work harder to complete the task no matter how challenging it is (LeFrançois, 2012).

There are some limitations to this study that needs to be addressed. Firstly, the sample size involved only five participants hence the findings cannot be generalized to all the parents of children with ASD in Malaysia. Secondly, the sample size was from developed cities in Malaysia. This may have biased the results as parental involvement in rural areas may be different. Suggestions for future research include understanding the relationship between parents' career level or status on their involvement with

the child's treatment, and effective strategies to change parents' behaviours to increase the skills and duration of involvement in their child's treatment.

Overall, ABA therapists' definitions of parental involvement shows that they desire and expect certain types of parental involvement to be helpful to the ASD child's treatment. Therapists also understand factors that may influence parental involvement and appear to be sympathetic, but this does not diminish the importance of getting the parents involved in their child's therapy.

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Conclusion

This study aimed to explore therapists' perceptions of parental involvement and the factors that lead to involvement. Parental involvement has been shown to be an important indicator of treatment outcome hence findings from this study will be useful for both therapists and parents to further understand this topic. Although this study has a small sample size, and the findings are not conclusive, the study to some extent can provide valuable information on how therapists perceive involvement and the factors leading to it. A greater focus on how to improve involvement could be beneficial for the therapist, parents, and the child.

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