

Parental Roles And Barriers: Love As Method (ABA) Therapy Support For Students With Autistic Disabilities

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Abstract

Autism is a brain disorder that is usually irreversible. However, the symptoms that appear can be reduced with appropriate therapy. The success of the therapy program for autistic children is influenced by the role of parents. This study aims to determine the role of parents with autistic children and their barriers to the support of Lovaas method (ABA) therapy. Using a qualitative research design, data were collected through interview techniques to 10 parents who have autistic children and then data were analyzed in the form of thematic analysis using NVivo software. The results showed that from the theme of the role of parents, 5 sub-themes were obtained, namely making time, cooperation, family support, evaluating progress and financial support. The most difficulties experienced by parents in carrying out their role towards therapy support are taking the time to deliver to the therapy place, repeating material at home, and the distance from home is too far.

Keywords: Parents role; therapy support; Lovaas method; Autistic children

INTRODUCTION

The East Java provincial social service office noted that the prevalence of children with autism in East Java Province in 2015-2020 increased from 23.99% in 2015 to 29.16% in 2020. (Makhmudiyah, 2023, p.58) This condition reflects that the increase in the number of autistic children in East Java is very striking. Patients with autistic children in East Java Province have continued to increase in the last five years, increasing by 5.17% (Makhmudiyah, 2023, p.58). From the preliminary study conducted at the place where the researcher teaches, namely at Embrace Hope Homebased Therapy and Athalias Blessing Surabaya, out of a total of 25 students there are 13 (52%) students diagnosed with autism from various ages ranging from 3 years old-16 years old.

Autism or commonly called ASD (*Autistic Spectrum Disorder*) is a complex and highly variable developmental disorder of brain function (spectrum), usually involving communication, social interaction and imagination (Ningrum, et al., 2017, p.142). Disorders of brain function are usually *irreversible* or conditions that cannot return to their original state. However, autism is *atreatable* condition, meaning that the brain disorder cannot be corrected but the symptoms that appear can be reduced with appropriate therapy so that children with autistic conditions can also have more adaptive abilities to their environment. The goal of therapy for children with autism is to reduce behavioural problems and improve their learning and developmental abilities, especially in the use of language. This goal can be achieved well through a

comprehensive and individualised therapy program (Hasnita, E, 2015, p.2). One method that is often used because it has proven effective is the *Lovaas* method therapy, which is a therapy developed from ABA therapy (*Applied Behaviour Analysis*).

ABA therapy is very representative for overcoming special children with symptoms of autism. Because it has measurable, directed, and systematic principles as well as wide variations that are taught so that it can improve communication, social and fine and gross motor skills. (Sari, S.P,2018,p.49)

(Imania, 2018, p.60) Imania also concluded in her research that the *Lovaas* Method / *Applied Behaviour Analysis* (ABA) is a method that teaches discipline where the curriculum has been modified from daily activities and implemented consistently to improve significant behaviour. Compliance and eye contact are the main keys in the application of the Lovaas method, without the mastery of these two abilities children with autism will be difficult to teach other behavioural activities.

According to Nuraeni.R (2019,p.16) the success of this therapy is influenced by several factors, namely the severity or mildness of the degree of autism, the age of the child when first treated, the intensity of therapy, the method of therapy, the child's IQ, language skills, behavioural problems and the role of parents and their environment. The role of parents in the therapy process is very influential to get maximum results. So between therapists and parents there must be harmonious cooperation. If the child is only given a program or

material at the place of therapy and at home is not applied, the results are not optimal.

In the place where the researchers took the data, the number of autistic students is more than 50% of the total number of students undergoing therapy there with a diverse age range. Inclusion criteria include : students with a diagnosis of autism under the age of 10 years, students undergo ABA therapy both at the centre and at home (homebased) we found 10 children that fit that inclusion criteria. Of the 10 children who underwent ABA therapy, only 4 underwent therapy at home (homebased) while the rest underwent therapy at the centre /institution. The reason parents choose to conduct therapy activities at home was more about practicality, due to the difficulty of transporting them to therapy at the centre.

ABA therapy must be carried out intensively so that maximum results can be obtained. The same thing was also conveyed by Amin.B, et al., (2022,p.56) that ABA is the only form of therapy for children with autism spectrum that requires 40 hours per week (5-8 hours every day) and one-on-one sessions in a continuous period of 2 years or more. To achieve 40 hours a week is difficult, so it is recommended to do intensive therapy by a therapist for at least 90 minutes/session with a frequency of at least 5 sessions/week, then the rest will be done by parents at home with direction from the therapist. However, in practice, intensive therapy for 5 sessions/week is more difficult to do because of many considerations from parents. The therapy given to each child with autism will indeed be more effective if it involves the active participation of parents. The goal is for each parent to feel that they have a stake in the progress their autistic child makes in each phase of therapy. In other words, parents do not only leave the improvement of their autistic child to the experts or therapists but also determine the level of improvement that needs to be achieved by the child. Thus, a stronger emotional bond between parents and their autistic child will be formed and this is expected to support the child's emotional and mental development to be better than before (Betha Y, et al, 2016, p.4).

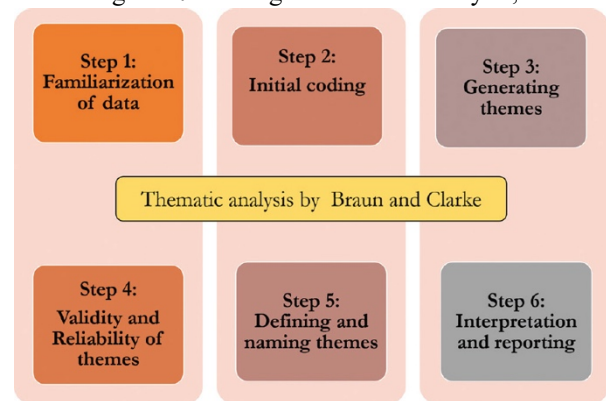
So far, there are not many therapeutic institutions that really involve parents in the therapy process, because many therapeutic institutions only focus on the child. With this research, it is hoped that there will be more therapeutic institutions that involve parents in the child's therapy process, not only by providing homework but also involving in making programs and evaluating children's programmes. So that the child's progress will be more quickly achieved and also consistent.

METHOD

This study aims to find out the role of parents with autistic children and the barriers to *Lovaas* method (ABA) therapy. This study used a qualitative approach by conducting interviews with 10 parents of children with autistic disabilities. The interview guide used included questions on the role of parents. Interviews were conducted face-to-face and whatsapp voice calls and were recorded using both external recording devices and

recording devices from mobile phones. Prior to the interviews, the researchers explained and provided full information about the study. Participation in this study was entirely voluntary and all answers given were kept confidential and no personal identity was disclosed. Participants had the freedom at any time to end participation during the interview. At the beginning of the interview participants received a brief introduction explaining the background and purpose of the research, as well as providing detailed information about the purpose, interview process, and use of transcripts. Participants who chose to become respondents signed a consent form before participating. Once the interview recording files were obtained, we used verbatim for transcription. Thematic analysis by (Braun & Clarke, 2006) with six stages was used to find patterns and meanings from each participant (see figure 1). NVivo software was used to organise the data collection for analysis purposes.

Figure 1. Six Stages Thematic Analysis,



Source Braun dan Clarke, 2006

The study was conducted on parents of students from the Athalias Blessing and Embrace Hope Surabaya therapy institutions with a diagnosis of autism who were under 10 years old and were undergoing the ABA therapy process both at the centre and at home. Data collection was conducted from 5 December to 15 December 2024. A total of 10 parents volunteered to be participants in this study.

RESULTS AND DISCUSSION

Based on the thematic analysis of the interviews, the main theme is the role of parents with sub-themes: (1) Making time, (2) Financial Support, (3) Family Support, (4) Cooperation, (5) Progress Evaluation.

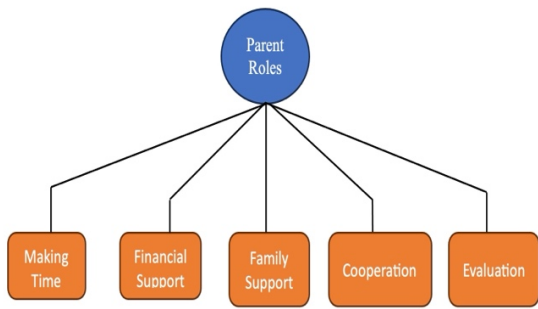


Figure 2. Emerging themes and sub-themes in the research

Of the 5 (five) sub-themes above, after making a hierarchy chart, it will be seen that each has its own portion. The one that has the largest area is Taking time then followed by cooperation, evaluating progress, family support then the last is financial support.

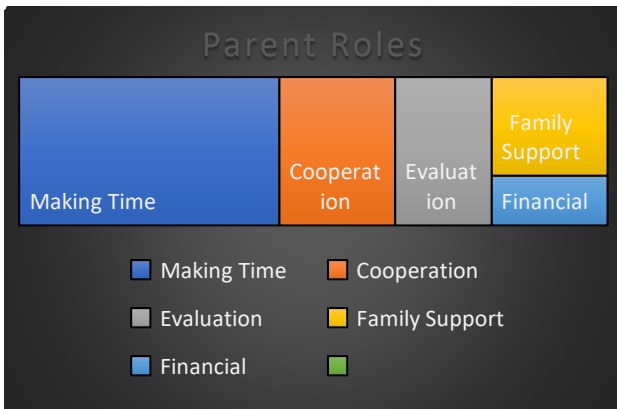


Figure 3. Hierarchical Chart of Parents' Role in Supporting Lovaas Method Therapy

The Role of Parents of Students with Autistic Disabilities in Lovaas Method Therapy

Making Time

It can be seen from the diagram below (Figure 4) that most of the participants are active workers (7 participants) and the rest (3 participants) are housewives. In his research Salsabila, et al., (2023,p.220) said that there are factors that influence the success of childre's therapy, namely (1) the duration of therapy time (2) the severity of the level of autism, (3) the age of the child at the first time of therapy, 4) the intensity of therapy. In line with Handoyo's opinion in (Saptasari et al., 2017) other factors such as: (5) the child's IQ, (6) the role of parents. The role given by parents is very beneficial for the optimal development of autistic children, parents have a great influence on child development around 92% while teachers and therapists have 3-4%. It takes more effort for parents who both work to arrange a schedule to take their

children to the therapy centre. Usually there is a special schedule for taking turns delivering or hiring special caregivers for children, of course not all parents can afford to hire special caregivers. One solution is *homebased* therapy (therapy at home), namely by bringing therapy to the house can be a solution for parents so that their children can therapy without having to drive to the therapy service centre, but of course it will affect the cost of therapy which becomes greater than coming to therapy at the therapy service centre.

'I think it is time management, because the demands of ABA are many but it is still difficult to do, we still lack a lot there. usually use the time available and usually I ask my wife. and I as a parent of an abk it is quite difficult to really obey recommendations such as playing in nature but it is difficult to do' (S9).

'The difficulty so far is to repeat the material at home, because we both work in shifts. So we find it difficult to divide the time...'' (S4)

'As for repetition, honestly it's not diligent. Mostly we just do simple repetition...'' (S7)

'Usually I or you repeat the homework given by the therapist, but it is not optimal because of time constraints. But we try as much as possible to repeat the material in our spare time' (S9)

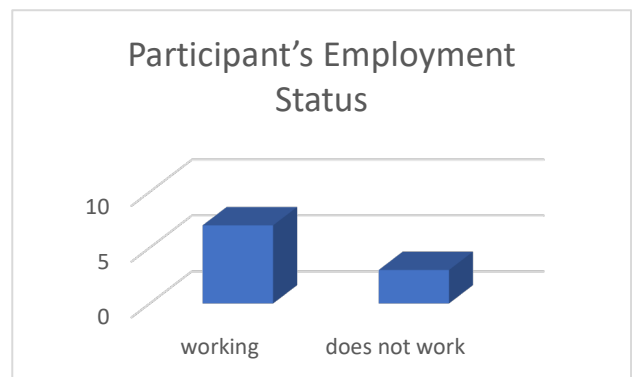


Figure 4. Participant's Employment Status Chart

Cooperation

As a parent of a child with autism, mutual support between spouses (husband and wife) and extended family plays an important role. Especially for couples who both work, understanding and cooperation are needed to be able to complement and support each other so that the child's therapy programme can run optimally. The role of parents in this thing is very much needed, so parents must work together for their children who have autistic disorders, in this thing the role of parents is very influential on the development of their children. Whether it cooperates with therapists or caregivers about the intake of nutrition and gluten therapy for the development of the brain and concentration of children (Syaputri, et al., 2022, p.563).

In parents where only one of them works, it is more dominant for the mother to take care of all the child's needs for therapy such as taking the child to the therapy centre, repeating the material taught at home, monitoring the progress of therapy results and coordinating with the therapist, maintaining diet and diet is also done by the mother. In parents who have more financial capacity, the mother's role will be partly replaced by a baby sitter. Whereas in parents who are both active as workers, the roles will be done alternately, so it takes awareness and good communication between the two.

"...last time I talked about the problem of playing to increase sensory is my responsibility but to talk to his mama because dave is more obedient to his mama. and to take care of other tasks for his mama, art is also quite helpful." (S3)

"We try our best to repeat. For repetition, it's more her mum, but if it's just her mum dzaka is less obedient, but if it's just me dzaka is like blank maybe because of reluctance. But if we both teach together, the results are better." (S4)

"It must be mostly me because his dad is in the office. I'm definitely 90% of the time. If my mum is there, I can also go with my mum but I always go with her. Unless it's a weekend, sometimes he also takes me. His father also helps to get ready in the morning" (S7).

Progress Evaluation

In terminology, several experts give Magdalena.I, et al. (2020, p.247) wrote opinions about the meaning of evaluation, that evaluation means an action or process in determining the value of something. When therapy is carried out, the hope desired by parents and therapists is the progress of the child's condition. So it is necessary to conduct regular evaluations both daily and monthly. The therapist/teacher will report learning outcomes both verbally to parents and write it in the liaison book. If parents do not pick up their children, they can read the daily learning results from the liaison book. The activeness of parents and therapists to communicate well with each other to pay attention to the progress of the child during therapy. If there may be difficulties that arise, especially when parents repeat the material at home, then with good communication the therapist can provide input. Therapists must also be proactive in reporting progress to parents, and provide assignments to do repetition at home so that children will be more consistent in responding to the material.

"We are together, but children are more obedient to their father, or reluctant to their father." (S7)

"The therapist and shadow teacher also report the results every day and after every therapy session. So I have no difficulty getting information" (S2).

"Her mum often monitors" (S4)

Family Support

According to Purnama Sari Mamonto, D. (2019,p.56) states that family support is the attitude, actions and acceptance of families towards patients with autism. Family support is also an important factor so that parents can carry out their role optimally. Family support that is usually seen is being able to cooperatively work together to increase the role of parents in therapy. For example, when parents work, the one who takes them to the therapy centre is their grandparents. Then it can also be worked together to have the same response when needed, usually related to compliance. When the child is not allowed to use mobile phones for too long, then everyone in the house including grandparents will ensure that it will happen. Participating in repeating the material at home together with parents will enhance the child's therapeutic development.

"My grandparents support me every morning to greet abim like what I do to abim. My husband supports abim's process including from my husband's family" (S1).

"My family just supports me..although they don't really interfere." (S7)

Financial Support

Having a child with special needs in the family is certainly a challenge in itself, because children need a lot of support from parents and family. The need for therapy for autistic children is the most important thing, and the therapy undertaken is sometimes not only 1 type of therapy. Rather it can be a combination of various therapies such as Sensory integration therapy, speech therapy, occupational therapy, behavioural therapy etc. this is of course quite influential on expenses in the family (increasing the financial burden on the family).

"...financially, yes, but when it's worth it, it's not a problem, energy and time" (S5).

"If we talk about funds, the funds are not small. Time is more important" (S7)

"Apart from that, it is also a financial problem, because I only work as a kindergarten teacher and his father is also not a permanent worker. But yes, I try to make an effort for my child to get therapy even though it cannot be idela in frequency for 1 week. It should be at least three times, but I only teach once and the rest I teach myself to save money." (S10)

Barriers to the Role of Parents of Students with Autistic Disabilities in Lovaas Method Therapy

Making Time

It can be seen from Figure 3 that the biggest obstacle in carrying out the role of parents towards supporting Lovaas (ABA) therapy is taking the time. The barriers that arise in making time are (1) Difficult to make time to repeat the material, (2) Can't do intensive therapy because no one takes them, (3) The distance between the therapy place and the house is too far (4) afraid of children getting tired and bored. Of the problems that arose, making time to repeat the material was the most expressed by participants.

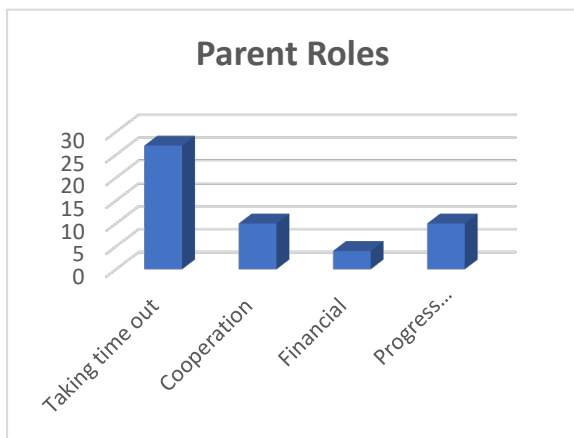


Figure 5 : Parental Barriers Chart in Carrying out the role For Parent

The frequency of *coding* (repeating material) appeared most frequently in the Nvivo application. The success of ABA therapy depends on several things, one of which is that it must be carried out intensively or frequently repeated. ABA therapy that is less intensive will affect the success of the therapy. Therapy conducted by therapists only has a maximum duration of 120 minutes, so repetition at home is needed to increase children's understanding of the material provided.

"..the difficulty is to be consistent both for repetition and different treatment from parents to grandparents." (S4)

"Consistency, because there is not much time and I am busy, sometimes I can stimulate and sometimes I can't, that's what makes it difficult" (S8).

Cooperation

The challenge that arises is that only one of the parents plays a dominant role in taking care of the child's therapy, this can happen because the father focuses on working so that only the mother plays a role in terms of child therapy. However, there are also some cases where even though the father works, he is still willing to help the mother during the weekends. The type of work of parents also affects the

flexibility of parents in making time. There are also some mothers who are provided with nanny facilities to help.

".....especially his father, he is a gamer if he plays, he forgets about his wife and children...." (S5)

"Usually the one who takes care of it is mbak yanti." (S6)

"It must be mostly me because his dad is in the office. It must be 90% of me from the beginning." (S7)

"I was told by mbak susnya because me and her papa work."(S9)

Family Support

From the results of the interviews, there were several participants who at the beginning after finding out that their children were diagnosed with autism could not accept their children's conditions, and there were also some whose grandparents could not accept the condition of their grandchildren, so they were less supportive when the child would be given certain therapies to stimulate their development. Some took time to convince family members who still did not accept, but there were also those who did not pay attention and continued to seek therapy for their children. And most of them finally accepted the condition of their children and grandchildren after seeing significant progress from the results of the therapy undertaken. Although accepting entirely may still be difficult, at least they can start to work together to help the role of the child's parents (especially when the parents work).

"At first, my husband still couldn't accept that it was autism. He thought it was just an ordinary delay due to lack of stimulation. But seeing that until the age of 4 the child still did not speak, finally the husband began to give permission to look for therapy outside" (S2).

"Initially, all the family, both from my side and my wife's side, were denial and always said, 'a boy must be late in talking', but after communicating well, they began to understand. Especially after the child's therapy there was a change for the better, then his grandparents began to accept. Although until now, if we say that the child has mild autism, he also refuses to say "don't say autism" (S4).

"My husband is denial too, he only feels stressed but there is no follow-up. My parents were denial and insisted on taking care of Elda themselves, after that they accepted and then brought her to therapy at Soetomo, after that my mother-in-law was sceptical and disagreed and finally gradually accepted and took Elda to therapy and every time they saw Elda's progress they cried." (S5)

"From my family, they all accepted, even requiring the child to live in Surabaya first, because in Ambon city there is no suitable therapy place. But my husband's family still

(thought) it seems like the child is fine, just late, but it will get better over time. But after 3 months of therapy in Surabaya, Ivanka has made a lot of progress, finally the husband's family began to accept" (S6).

Progress Evaluation

From the results of interviews with participants, there were no significant problems. Parents actively monitored the progress of their child's therapy, and therapists also proactively provided reports both verbally and in writing regarding the progress of therapy and what should be repeated at home.

"Everyone monitors the process of elda's therapy, everyone asks, every night they call, yesterday was also elda's birthday, elda suddenly looked at uti and said "that's darling" they just felt there was progress" (S5).

"Her father actively monitors the progress of the therapy, some time ago her father wanted the child to go to school, so the massage therapy was stopped so that Ivanka would not be too tired" (S6).

"Praise God, Michella has made a lot of progress. So far, the therapy centre is always up to date to report the results of therapy." (S9)

Financial Support

From the results of the interviews, some participants said that financial problems could still be pursued, but there were also some participants who claimed to be quite burdened and could only fulfil part of the child's therapy portion. So that some children with poor financial conditions cannot provide intensive therapy for their children and choose to do it themselves. However, in practice, when parents are involved in teaching / repeating material at home, several obstacles arise, namely children who are less obedient when learning with parents, inappropriate teaching methods, and not being able to repeat intensively due to time constraints.

"Apart from that, it is also a financial problem, because I only work as a kindergarten teacher and his father is not a permanent worker. But yes, I try to endeavour for my child to get therapy even though it cannot be idela in frequency for 1 week" (S10).

"Financially, we can still find it, time can still be organised, but it is difficult to handle children's emotions when they suddenly tantrum when they are grabbed on the way to or from work" (S7).

"For financially, thank God, we are still given by Allah, for me the difficulty is to be consistent both for repetition and different treatment from parents and grandparents." (S4)

CONCLUSION

The objective of this study was to determine the role of parents towards the support of Lovaas method therapy and its obstacles. The study used a qualitative method using interviews used to gain an in-depth understanding of the role of parents with autistic children on the support of Lovaas (ABA) method therapy. There was 1 major theme, namely the role of parents, and has 5 sub-themes, namely (1) Making time, (2) Cooperation, (3) Evaluation of Progress, (4) Family support, (5) Financial support. The most frequently expressed problem was the difficulty of parents to take the time both in terms of repeating the material, taking the child to the therapy place, dividing time between work and the role of support for the implementation of therapy both in therapy institutions and home therapy. For future research directions, the current study suggests investigating other external factors such as family knowledge and the quality of therapists/therapy institutions. This is important to be able to improve the quality of therapy in children so that the progress of therapy will be better.

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