

Online Autism Literacy to Improve Acceptance of Mothers of Children with Autism Spectrum Disorders



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ABSTRACT: The spectrum of autism developmental disorders is vast and diverse, ranging from mild to severe impairments. If parents lack knowledge about autism, maternal acceptance levels tend to be low. Autism literacy through the internet serves as a medium to provide beneficial, extensive, cost-effective, and easily accessible information and knowledge. This study aims to assess the effectiveness of online autism literacy in increasing maternal acceptance of autistic children. The research utilized a single-subject design, involving only one subject, following the ABA Single-case Experiment Design. The single-case experimental method was employed in this study, where autism literacy intervention was delivered through the website www.careautism.wordpress.com. A Maternal Acceptance Scale was used to evaluate the subject's psychological state before and after the intervention. The research's significance lies in providing empirical evidence on the effectiveness of online autism literacy in enhancing maternal acceptance of autistic children. Visual inspection and descriptive analysis methods were employed for data analysis. The study's results indicate that autism literacy intervention through the internet can improve maternal acceptance of autistic children, with an increased mean score between the baseline and intervention phases.

KEYWORDS: online media, literacy, autism, parental acceptance.

I. INTRODUCTION

Disability is the inability of a person due to intellectual, psychiatric, cognitive, neurological, or physical impairment, which can be permanent. It results in limitations in social interaction, communication, learning, mobility, decision-making, and self-care, requiring ongoing social support (Radissa et al., 2020). People with disabilities often face barriers in accessibility, education, employment, and participation in social life. According to statistical information from the World Health Organisation, there are more than one billion people worldwide living with disabilities. In Indonesia, based on statistical information from the Central Statistics Agency (BPS), there were approximately 12 million people with disabilities in 2018. A person with a disability experiences various limitations and has various types, one of which is autism spectrum disorder.

Autism or autism spectrum disorder (ASD) is a neurological condition that affects a person's social development, communication and behaviour. The Diagnostic and Statistical Manual of Mental disorder (DSM-V) defines autism as a developmental disability that affects various aspects of activity or life characterised by qualitative communication, behaviour, social contact, and hobbies (Lord et al., 2018). In this condition, individuals with autism experience difficulties in interacting socially, communicating with others, exhibiting behaviours appropriate to certain situations, and showing limited interests and activities. The different characteristics of autism in each individual and the complex problems they have require comprehensive treatment from parents, medical practitioners or doctors, psychology professionals, therapists, nutritionists and government agencies. (Hyman et al., 2020).

Based on the results of research by Ogretir & Ulutas (2009) Parents and carers of children with autism often report increased levels of stress, depression and anxiety. The study revealed that the highest level of parental stress is experienced when the child is still in the early developmental stage, namely when the child's behaviour has not been established so that they still need to undergo intensive therapy and are still in the early stages of school. Parenting stress in parents has a lasting impact such as parental acceptance of the child, psychological disorders, mental disorders or psychopathology, unstable emotions that interfere with parent-child relationships (Bromley et al., 2004). Negative impacts will be more experienced by mothers, such as physical and emotional exhaustion, decreased physical health, increased risk of disease, sleep disturbances so that these impacts

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affect the mother's ability to care for her child. Mothers who experience emotional disturbances or high levels of stress have a decreased or low quality of interaction and are generally experienced by mothers in early adulthood to middle adulthood (Lovejoy et al., 2000). Less harmonious relationships, less mutual support in the family environment can affect individual development and overall family well-being (Conger et al., 2010). The stress experienced by parents of children with GSA can affect parenting patterns so that children's development tends to be negative (Ogretir & Ulutas, 2009).

Baumrind suggested that parenting patterns can be divided into authoritarian, permissive, ignoring/rejecting, and authoritative. Various follow-up studies were conducted by other researchers. Rohner developed the concept of PARTheory (parental acceptance-rejection theory) (Rohner, Khaleque, & Cournoyer, 2007) that defines parental acceptance as parents' perceptions of their care for their children. Parental acceptance comes in the form of strong attention, love, and respect, trust, good communication, and mutual involvement so that children feel psychologically safe from their parents. Parental acceptance is included in the warmth dimension of parenting which is derived into several aspects, namely parental warmth, parental coldness, child abuse, child neglect, and other forms of child rejection. The theory contains the dimensions of parental warmth, which is a continuum divided into 4 categories, namely: (1) warmth and affection; (2) absence of affection; (3) hostility and aggressiveness; (4) indifference and neglect; and (5) rejection in other forms.

Research conducted by Reinke & Solheim (2014) found that parents, especially mothers with children on the autism spectrum, tend to seek online support from other parent communities through social media and online forums. They use these platforms to share experiences, obtain useful information, and seek emotional support in dealing with the challenges faced in caring for their children. The availability of this information can influence parents' acceptance of their child's condition. By having more knowledge, parents can make better decisions in caring for their child.

Since 1970, Health Education has recognised the term 'health literacy' and has seen it as a social policy. Health literacy encompasses an individual's ability to access, read, understand and utilise health information effectively to make accurate decisions and follow treatment instructions (Reber & Reber, 2010; Roundtable on Health Literacy, 2012; Vandenbus, 2007). With the advancement of information technology, the internet has played a very important role as a medium in improving literacy. Parents who have limited understanding of autism symptoms and treatments may experience low levels of health literacy (Grant, 2016). When parents become aware of autism symptoms in their child, they often experience high levels of stress and face difficulties in finding relevant information to determine effective interventions for their child. To overcome this challenge, parents can utilise the benefits of information technology, such as websites, which can be a source of information and also provide the emotional support needed (Grant, 2016).

Parents can utilise websites as a source of information and emotional support. There are several advantages in utilising websites, including (Zaidman-Zait & Jamieson, 2007): (1) easy and quick access to information, (2) affordable cost to access the information, (3) availability of information around the clock, (4) data security and anonymity in accessing information, and (5) the opportunity to communicate with parents through online communication tools. However, there are some drawbacks that need to be considered in using websites as a source of information, such as the volume of knowledge or diverse information, as well as the absence of an official review or assessment of the accuracy of the information provided. Based on previous research, that parents may exploit are more likely to trust sources obtained through sources managed through trusted organisations or by professionals, compared with information provided by some parents who (Bernhardt and Felter, 2004; Taylor, Alman, & Manchester, 2001).

In this study, researchers prepared an autism literacy programme through the use of the internet as an alternative to provide an understanding of autism to parents of autistic children. This literacy programme integrates the concept of psychoeducation about autism. Through a cognitive-behavioural intervention approach, information provided to individuals can influence cognitive, emotional and behavioural changes. Psychoeducation is one form of intervention that adopts a cognitive-behavioural approach, and in this context, it is conducted for parents as a form of experiential learning. Psychoeducation for parents of autistic children is usually conducted through face-to-face sessions. However, there are several obstacles such as limited time, location, energy, and cost. The objectives of face-to-face psychoeducation are to improve children's language skills and interaction with parents, improve coping skills, reduce behavioural disorders in autistic children, and increase parents' acceptance and understanding of autistic children (Hidayati, 2013).

Based on the description above, the researcher revealed that parents react with confusion, anxiety, sadness, and tend to reject when their child is diagnosed with autism. This is due to parents' lack of knowledge about their child's condition and treatment, lack of understanding about self-management, and lack of information about the experiences of others who have autistic children. Therefore, it is important for parents of autistic children to obtain the knowledge and information needed to understand their child's condition, cope with the problems that arise, and show acceptance towards their child.

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Previous researchers have overcome the limitations of face-to-face psychoeducation by introducing internet-based psychoeducation Alexander & Grannum (2022) and (Vismara et al., 2013) conducted studies that used various media such as narratives, slide presentations, video examples, Applied Behaviour Analysis therapy exercises, video conferences, and websites. The results of these studies recommend the use of internet media as an alternative in providing psychoeducation to parents. The psychoeducation material delivered to parents is based on the Applied Behaviour Analysis (ABA) approach with the aim of providing knowledge about the recognition of signs and symptoms of autism, the diagnosis process, and the necessary treatment. Other researchers, such as (Brookman-Frazer et al., 2006), have studied the topic in depth, suggesting materials on stress management, self-control, problem-solving skills, and strengthening family function and social support.

Psychoeducation has the flexibility of a model that can be adapted to individual situations (Lukens & McFarlane, 2004). In one study, a psychoeducational approach through internet-supported literacy through a website and psychology consultation through Facebook was used. The aim was to change parents' behaviour through increased knowledge. The model of behaviour change through internet-based interventions (Ritterband et al., 2009) includes factors such as knowledge, motivation, beliefs, skills, cognitive restructuring and self-monitoring. Knowledge acceptance and individual learning processes are important in behaviour change (Fink, 2003). It is hoped that internet-supported autism literacy can help parents understand their child's condition, deal with problems, and accept their child better.

Research on interventions to improve mothers' acceptance of autistic children using online media is scarce. Therefore, this study aims to determine the effect of intervention with literacy materials about autism using online media to increase the acceptance of mothers of autistic children.

II. METHOD

The criteria for research subjects were: (1) mothers of autistic children in the age range of 3-8 years; (2) the child has received a diagnosis of autism spectrum disorder by a doctor or psychologist; (3) the mother's age ranges from 25-45 years; (4) the mother's last education level is at least high school or equivalent; (5) has the ability to use a computer or laptop; (6) has the ability to access email, Facebook, and websites without assistance; and (7) has a parental acceptance score in the low to moderate category. The instruments used in this study include the parental acceptance scale, subject consent sheet, diary, intervention session observation sheet, research evaluation sheet, and interview guide.

The research design was to use a single-subject design equipped with a number of subjects of 1 person and using the ABA Single-case Experiment Design research guide (Barlow & Hersen, 1984; Sunanto, Takeuchi, Nakata, 2005). Subjects followed the measurement stages, namely before intervention, during intervention, after intervention, and at follow-up. Descriptive analyses based on diaries and interview data were used to complete the research data.

The purpose of the intervention was to present material to the subject about the meaning and symptoms of autism. The intervention provided in this study was based on the Care-Autis literacy module, which included knowledge about autism, self-management, information about other parents' experiences, and experiences of children with autism. The literacy module is delivered through a website at www.careautism.wordpress.com. The intervention was also complemented by a psychology consultation service through Facebook that only accepted members or followers of the research subjects. Face-to-face interviews were conducted between the subjects and the facilitating psychologist twice during the A1 baseline and once during the follow-up session. Subjects followed the intervention by reading information and knowledge materials on the website for 1-1.5 hours per day. The subject accessed the website within 8 sessions. Subjects can conduct online consultations with psychologists via email.

The visual inspection method is used for quantitative data analysis by taking into account the results of the level of stability (level stability), direction tendency (trend/slope), and the level of change in the source or data (level change Kazdin, 2011; Barlow & Hersen, 1984; Sunanto, Takeuchi, Nakata, 2005). The assumption used in measuring the level of stability is if 80%-90% of the data is at 15% above the mean then it is said to be stable. The split-middle method was used to analyse directional tendency using the median value of the data. Analysis of the level of change in data between conditions is calculated by reducing the last score in the first condition with the first score in the second condition. An overview of the subject's psychological dynamics was obtained through interviews with the subject.

III. RESEARCH RESULT

Subject descriptive data based on observations and interviews can be used to analyse the subject profile. The subject of this study has initials as Mrs C and is 32 years old with a D3 educational background. She has two daughters aged 7 years and 2 years. At the age of 3, Mrs C's first child was diagnosed with autism. When she found out about this condition, Mrs C felt confused and did not know what to do. She had no support from family or friends who could help her. Mrs C was also limited in actively seeking information, with sources of information limited to the doctor or therapist working with her son. This hindered timely,

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targeted and sustainable treatment for her child. In addition, Mrs C also lacked support from her husband who was busy working all day. Based on observation data at school, Mrs C tended to be alone and did not join other parents who were waiting for their children. She sat more and was seen accessing social media through her mobile phone rather than discussing or interacting with other parents.

During the intervention process, Mrs C experienced difficulties in accessing websites and using a laptop. However, she felt that the intervention provided reminders about the symptoms of autism and the basic treatments needed. She also received materials on self-management which greatly helped her in reducing anxiety and stress in her daily routine. Mrs C felt more in control of her emotions when dealing with her son's behaviour. During this process, Ibu C gained an understanding and enlightenment that the way she cares for her children has a huge impact on their behavioural responses. She realised that if she wanted to see positive changes in her children, she needed to change her behaviour, parenting approach, and the way she responded to her children's emotions, especially in dealing with their challenging behaviour.

The measurement instrument in this study was a parental acceptance scale adapted from the parental acceptance scale developed by (Rohner et al., 2012) Information about the results of the measurement of the research scale can be found in figure 1 which shows that Mrs C experienced a significant increase in parental acceptance from the pre-test to the post-test phase and decreased in the follow-up phase.

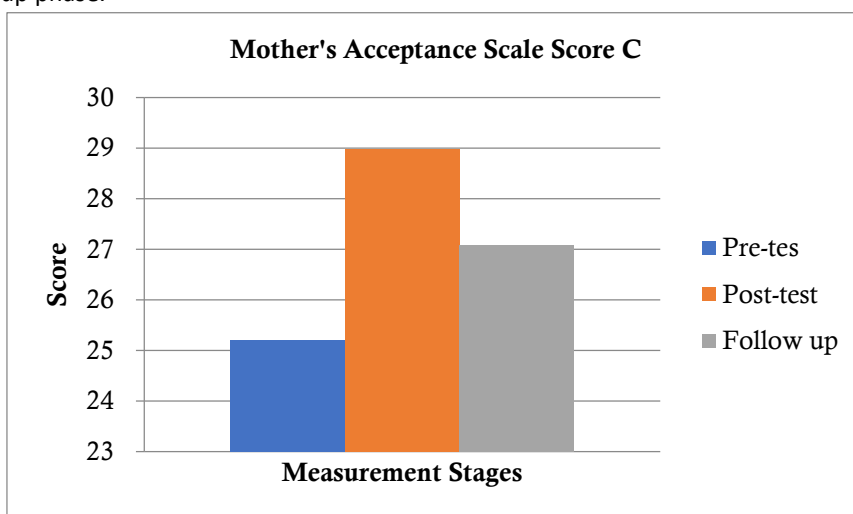


Figure 1. Measurement Results of Parental Acceptance Scale

The findings of the data analysis of this diary are the influence of negative events experienced by the subject on the acceptance of autistic children. Negative events can come from the child's negative behaviour or situations and conditions from the environment (outside the child's behaviour) that make the mother experience negative emotions. If there is a negative event, the subject's acceptance tends to decrease. If there is no negative event, then the subject's acceptance tends to increase. The dynamics of parental acceptance influenced by this negative event can be seen in Figure 2.

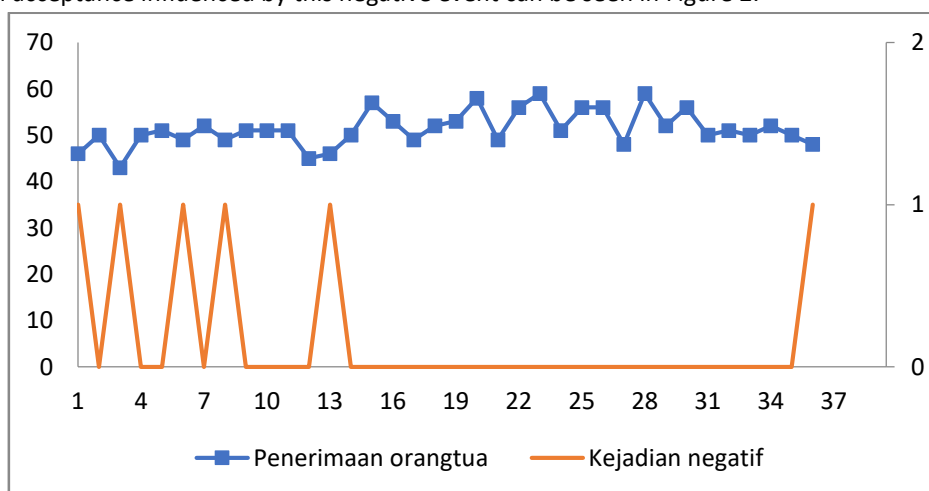


Figure 2. Mrs C's behaviour score in the daily logbook

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The level of stability, slope, and change in parental acceptance have been visually analysed using behavioural data recorded in the daily logbook. Variable stability analysis showed that Mrs C's acceptance in phases A1 and A2 had the same level of stability. Analysis of directional tendency using the split middle method showed a change in direction and level of change influenced by the intervention. In phase A1, there was no change in direction with the median remaining at 50. In phase B, there was an increase in the median from 53 to 56. While in phase A2, there was a decrease in the median from 51 to 50. The change in Mrs C's level of acceptance from phase A1 to phase B showed an increase of 7 points in a positive or improving direction. The direction trend (slope) of the subject can be seen in Figure 3.

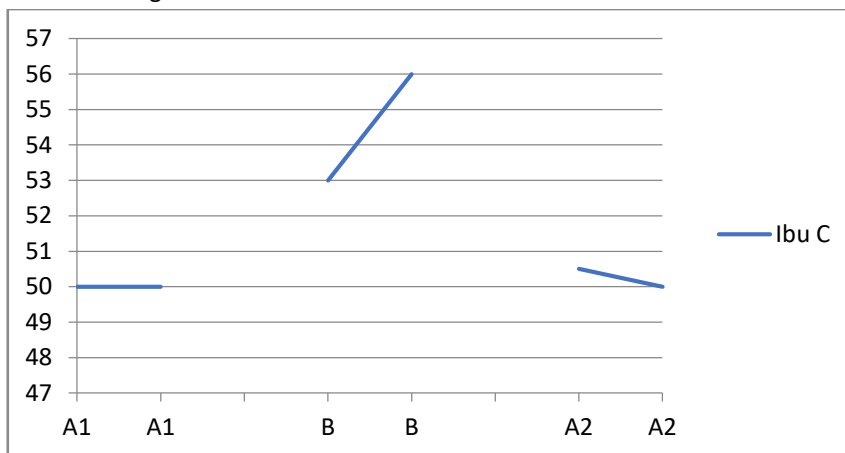


Figure 3. Directional Tendency (slope) Mother's Parental Acceptance C

DISCUSSION

The intervention on the subject is a form of literacy about autism provided through online media. This online literacy is also accompanied by references to other sources of information as an addition if there is material or information that is not understood. In addition, there are also references to psychologists who can be contacted to discuss daily activities, child behaviour, child development, communication with families about parenting, and other topics according to the subject's needs.

Knowledge and information about autism is needed by parents, especially mothers who care for and assist autistic children. Mothers are expected to have good enough knowledge to understand their children's conditions and be able to provide care, teaching and assistance at home so that autistic children develop better. Things that affect the psychological dynamics of parents of autistic children are educational background, parenting experience, knowledge about autism, socioeconomic conditions, and family factors as a social support system (Ergüner-Tekinalp & Akkök, 2004). Parents, especially mothers, are expected to continue learning because knowledge and information about autism often changes and develops as research and treatments progress. The learning process is also expected to change from conventional to more technological (Rohner et al., 2012).

The problems experienced by parents of autistic children are very diverse depending on the various aspects that affect Rohner et al., 2012; Arslı; (Gray, 2006). Parents can seek information and gain knowledge to overcome the problems that arise (Oosterling et al., 2010). In this case, the subject Mrs C did not have information when she found out about the autism diagnosis given by the doctor to her child. Mrs C lives in Jogja with her husband and two daughters. She felt overwhelmed with household chores and caring for her first child who was diagnosed with autism. Mrs C and her husband come from West Java province, so when they lived in Yogyakarta, they did not have an extended family support system in childcare. Within these limitations, Mrs C had limited abilities and support which made her rely solely on seeking information through doctors, therapists, teachers, or stories from other parents. (Fink, 2003) states that changes in new knowledge obtained can be shown by changes in attitudes, emotions, and behaviour in daily life. With the changes in knowledge that indicate a significant learning process in the research subject. Mother C gained meaning and enlightenment that the mother's response greatly influences the child's behaviour. In addition, the research subject realised that the parenting patterns obtained from her grandmother influenced Mrs C's parenting patterns for children. The subject got the meaning that the knowledge about autism was still very lacking and the subject also needed a partner or group of parents who could learn together. This shows that parents need to learn from this millennial generation.

According to research by (Ritterband et al., 2009) internet-based interventions can bring about changes in individual behaviour. Autism literacy focuses on providing knowledge, information and co-operation between parents, teachers, therapists and autistic children. In this intervention, psychoeducation focuses on the process of re-teaching through information sources in the website, while the process of psychotherapy through psychological consultation and daily self-monitoring records may not achieve optimal results. This may hinder the subject's behaviour change mechanism to be maximised.

IV. CONCLUSIONS

Conclusion

The results showed that there was an increase in parental acceptance in the research subjects. The researcher realizes that there are limitations in this study related to internet use. These limitations include using the internet before it is optimal for individuals, accessing websites, social media (Facebook), and using laptops. In addition, limitations related to subject inclusion criteria are the unbalanced level of knowledge and ability of subjects in accessing websites and the use of computers/laptops that are not measured. There are also limitations in the form of intervention, namely writing. However, these limitations can be overcome by making changes to the magazine, writing articles to be read and written in short, clear and easy-to-understand language, and equipped with appropriate images and videos. In addition, it is important to optimize the use of the internet as an intervention tool.

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