

Acceptance and Commitment Therapy (ACT) to Reduce Caregiver Strain in Mothers of Autistic Children

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Abstract- This research aims to reduce caregiver strain in mothers who care for children with autism spectrum disorder (ASD). This study was conducted based on the high caregiver strain experienced by mothers in the caregiving process. Such strain affects not only the mother's psychological well-being but also the child's. The current study was conducted using a one-group quasi-experimental, pretest-posttest design, in which the Acceptance and Commitment Therapy (ACT) intervention was individually implemented to four participants. Analyses were drawn from comparing quantitative and qualitative data from the pretest and posttest periods. Quantitative results showed that ACT reduced strain scores as measured by the modified caregiver strain index (MCSI). Qualitative results showed that ACT improved participants' ability to deal with caregiver strain. Participants reported having more positive feelings, ability to control negative emotions, and capability to deal with unpleasant events in their lives. Participants also obtained new knowledge and skills on how to deal with strain as a caregiver of a child with ASD. In conclusion, ACT is effective at reducing caregiver strain in mothers of autistic children.

Keywords: acceptance and commitment therapy, autistic children, caregiver strain

Introduction

Autism spectrum disorder (ASD) is a pervasive neurodevelopmental disorder characterized by impairments in the social, language, and communication functions as well as unusual behaviors (Mash & Wolfe, 2010). According to the Central Bureau of Statistics of Indonesia, there were approximately 140 thousand children below the age of 17 who had ASD living in Indonesia between 2010 and 2016 (Kurnia, 2014). The presence of a child with ASD in a family greatly influences the family dynamics. The time around the child's initial diagnosis with ASD is a particularly vulnerable time for the family (Taylor & Warren, 2012). Families not only have to adjust to the loss of the child they hoped to have but must also accept the child they have, as well as take on the challenging task of learning about ASD (Ruble & McGrew, 2007 in McGrew, 2014). Stress in parents of children with ASD is caused by having to deal with the symptoms of ASD. Challenges to be dealt with include challenges in communication and the expression of emotions as well as impairments in language exhibited by the child. Parents also have to be alert for children who engage in repetitive movements and can behave aggressively. Further they have to give extra nurturance needed by the child who is unable to care for himself or herself. Parents also need to take care of their child's education and navigate through other health institutions (Phetrasuwan, 2009).

Even though all members of the family play roles in the caregiving process, mothers typically take on the role of primary informal caregiver. This is due to the traditional role of mothers, in which it is the mother's responsibility to care for members of her family; mothers also act as informal caregivers for their children without ASD (Miodrag, 2009). Furthermore, as

caregivers, mothers tend to experience constant guilt while caring for their family due to their perception that they are unable to care for their family well (Abrahms, 2012). This motivates mothers to keep on striving in the caregiving process for their family. Wiener (2011) also added that mothers are assumed to have more time to be more involved in child care. Given this role, it is no surprise that mothers, as informal caregivers, are deemed to feel the most pressure compared to other members of the family.

Caregiver strain is defined as the caregiver's perception of all the problems they face throughout the caregiving process (Thornton & Travis, 2003). Caregivers of children with ASD are reported to have higher levels of strain compared to parents of children with ADHD, parents of children with other developmental disorders, parents of children with emotional and behavioral issues, and parents of children with other special needs (Kirby, White, & Baranek, 2015). One study has shown that the diagnosis of the child is a contributing factor to the level of caregiver strain (Lanfranchi & Vianello, 2012). Other than diagnosis, emotion management strategies, locus of control (Lanfranchi & Vianello, 2012), caregiving difficulty level (Stuart & McGrew, 2009), socioeconomic situation (Abbeduto, 2004), and magnitude of social support (Plant & Sanders, 2007) also contribute to levels of caregiver strain experienced by caregivers of children with ASD.

It is the task of mothers to assist their children with daily activities. These activities include self-care, such as preparing clothes and food. Ludlow, Skelly, and Rohleder (2011) stated that, when mothers help children with ASD perform such daily activities, they have to deal with impairment in social interaction, communication, and stereotypical behaviors. The child's inability to engage in normal social interaction and communication makes the mother's experience more difficult in terms of understanding what the child wants. Mothers often do not understand why a child cries or becomes angry all of a sudden because the child cannot express what he or she wants in words. These impairments also prevent the child from understanding what the mother has said, so that, in turn, the mother becomes frustrated because the child fails to understand. Mothers feel that they have to be able to control their emotions and find a way to empathize with the child's condition.

With all of the challenges faced by caregivers of children with ASD throughout the caregiving process, studies have found that caregivers of children with ASD have higher levels of depression and stress compared to caregivers of children with other developmental disorders (Carter et al., 2009; Estes et al., 2009). The caregiving process also has negative repercussions for the health and quality of life of the caregivers. The negative impacts often experienced by caregivers include somatic symptoms, high levels of anxiety, and poor health conditions when compared to the population in general (Robledillo & Albiol, 2015). A recent study found that the strain experienced by caregivers can have debilitating effects on their physical and psychological health as well as a high potential to disrupt the effectiveness of interventions for the child with ASD (Osborne, 2008).

Unfortunately, the availability of interventions that can adequately deal with caregiver strain is currently very minimal. Honea and colleagues (2015) conducted a systematic review on the topic of measurements and interventions done by nurses to alleviate burden and strain on families of cancer patients. They reviewed eight studies that specifically measured burden and strain. The interventions used were psychoeducation, supportive intervention, psychotherapy, cognitive-behavior interventions, massage, healing touch, respite care, multicomponent, and interventions used to increase the ability to accept.

This review concluded that, even though these interventions have positive psychosocial effects, there is no proof that they reduce the burden and strain felt by caregivers. Other studies have argued that the data used for this review were not sufficiently sound. Some even stated that the study was limited due to its small sample size. It is not yet known whether outcomes would be most improved by increasing the variety of interventions available, increasing the time caregivers have to practice their new skill, or making more use of available resources after the intervention (Keefe et al., 2005). Da Paz and Wallander (2017) did a review of interventions on mothers of children with ASD as a population. The review was done on the topic of interventions aimed at improving the mental health of the parents. Based on the thirteen studies reviewed, it cannot be concluded as of yet whether parents of children with ASD respond to methods aimed at increasing personal skills better than interventions that help them acknowledge and accept their feelings without judgment. The researchers had difficulties drawing a conclusion due to the limited amount of study replications. However, measurements of pre- and post-intervention scores regarding acceptance and commitment therapy (ACT) as an intervention and relaxation training revealed a positive increase.

Given the chronic nature of the disorder, children with ASD require extensive, if not lifelong, care (Robledillo & Albiol, 2015). The long duration of caregiving coupled with the fact that the condition is irrevocable causes mothers of children with ASD to be more likely to have negative thoughts and emotions. After a mother is able to accept her situation, she then needs to commit to her choices according to her values so that she can hold on to them (Stuart & McGrew, 2009). To achieve this goal, an intervention needs to be applied, specifically, an intervention that is able to help the mother understand her situation, consequently accept it, and eventually commit to the caregiving process.

ACT is a cognitive-behavior therapy that incorporates the principles of positive psychology. ACT consists of two main ideas: values-guided action and mindfulness skills. Values-guided action helps to clarify what is truly important in life, including values. After that, this intervention leads its users to use the obtained knowledge to guide, inspire, and motivate the achievement of set goals as well as to take actions that will enrich their lives. The mindfulness aspect of ACT involves a process that focuses on flexible living in the here and now. ACT is described in terms of six correlated processes and aims to encourage the goal of psychological flexibility, defined as the ability to access real personal experiences happening at the present time without having to avoid or try to detach oneself from one's surroundings. In addition,

ACT also helps individuals adjust their behavior to their surroundings to reach a meaningful end goal (Hayes et al., 2006). Through this intervention, it is hoped that caregiver strain experienced by mothers who are informal caregivers of children with ASD will decrease as mothers become able to have new perspectives toward their own uncomfortable feelings caused by the caregiving process. In turn, the standard of care for children with ASD is expected to improve as well. After going through this intervention, it is hoped that caregivers will be able to manage their tensions which will help them function well psychologically on a daily basis. The current study aimed to examine the application of ACT in reducing caregiver strain on mothers who care for children diagnosed with ASD.

Methods

Participants

The participant criteria for this study were mothers who were informal caregivers for a biological child diagnosed with ASD. The mother had to live in the same house with the child and to have held the role of caregiver for at least one year. The mother had to possess at least a high school diploma because ACT is an intervention utilizing several philosophies, strategies, and techniques requiring the users to have adequate verbal comprehension. Participants with at least a high school education were approximated to have the necessary intellectual capacity and verbal ability to understand the content in ACT. Participants had to care for the child for at least 20 hours per week. Participants also had to have pre-test scores that were greater than or equal to 14 on the MCSI and/or had to experience caregiver strain as determined qualitatively. Participants were also required to give their consent to be a part of the study and finish the ACT package.

The research team successfully recruited four participants who completed the intervention package. Each participant had lived through different durations of caregiving and had experienced financial, emotional, and personal strains. All four participants received the intervention at four different locations. Each location was chosen based on agreement between the research team and participants. Below is a brief description of each participant.

Desi was a housewife with a 6-year-old son. Desi's son was non-verbal, had inappropriate emotional expression, and his self-help skill, especially in toileting, was not developed. Her son's inability to talk caused significant stress to Desi as it was difficult for her to understand her son's needs and wants. Desi had been staying at home a lot ever since her son's diagnosis. She had withdrawn from her friends because she was embarrassed about her son's condition. She was also upset that her friends did not understand her feelings and situation as the mother of an autistic child.

The second participant was Sita. Sita was a housewife with two children, a 6-year-old daughter and a 3.5-year-old son. Sita's son was diagnosed with ASD when he was 18 months old. At that time the son was able to speak a few words. His emotional expressions were not as developed

as those of his peers. It took a lot of effort and time for Sita's son to learn about anything. This situation caused stress and tiredness for Sita. Whenever she felt stressed or tired, she would cry in the bathroom or retreat into her bedroom with the door locked so the children would not disturb her. Sita's husband was involved in most aspects of parenting for which Sita was very grateful.

The third participant was Fani. Fani had 12-year-old identical twin boys who had been diagnosed with ASD when they were 18 months old. Fani and her husband were employees who worked 8-4 on weekdays. While the parents were working, the twins were taken care of by a nanny. The nanny would leave after Fani arrived home from work. According to Fani, her sons were quite able to demonstrate self-help skills, with the exception of toileting. This made Fani worried. Furthermore, one of her sons stuttered. Another thing that caused significant stress for Fani was the difficulty of finding a suitable school for the twins. Often, she was tired and fatigued because of her sons' behavior. This led her to think that the future was bleak. Fani had sometimes discussed her sons with her co-workers. However, whenever something new arose, she would feel distress, especially about their future. Fani also thought that she didn't spend enough time with her twins. This was due to her work, but nevertheless she still felt guilty.

Nia was a housewife with a 4-year-old son. At this time she was separated from her husband and living with her aunt and the aunt's family. Nia's son had been diagnosed with ASD when he was 27 months old. Her son was non-verbal, hyperactive, and very sensitive to many types of food. He babbled and had underdeveloped self-help skills including toileting. The son's situation caused significant stress for Nia as it was difficult for her to understand her son's needs and wants. However, Nia did not feel burdened by taking care of her son. What troubled her was the lack of emotional support from the significant people in her life, including her friends.

Procedure

The research design was a one-group before-after (pretest-posttest) design. Research participants were found by sharing information on the participant criteria through social media such as Facebook and Path, as well as broadcasting on a few chat groups on WhatsApp. The research team also shared the information directly with their colleagues. When a volunteer matched the criteria, she was invited to fill out the MCSI measure online. Upon completion of the measure, the potential research subjects would be contacted and interviewed so a general description could be obtained. Participants were selected based on their characteristics. The interview was semi-structured with a set interview guide. After the initial screening, the research team then selected the participants based on the selection criteria. Participants were then asked for their consent to be a part of the study. This study was approved by the ethics committee of the Faculty of Psychology, Universitas Indonesia.

Quantitative evaluation on this study was done by examining whether or not there were changes in the levels of caregiver strain for each participant. These changes were indicated by score

changes as measured by the MCSI (Travis & Thornton, 2003), which was filled out by the participants during pre-intervention and post-intervention assessments. Qualitative evaluation was conducted through interviews. Participants were expected to be able to describe the changes they had experienced, if any, and how they felt after the intervention.

The ACT intervention utilized in this study was adapted from a module developed by John T. Blackledge (2004). Sessions in the intervention included discussing the roots of problems, filling out the value assessment rating to identify the participant’s priorities, talking about conditions that may occur during unpleasant experiences, describing strategies attempted thus far and their effectiveness, and making analogies related to each participant’s condition. Participants will then be encouraged to recognize the obstacles they have dealt with and how they have overcome them, and finally to learn relaxation techniques.

The module, developed by John T. Blackledge (2004), was modified to fit the present research context. One of the modifications we made was converting the 14 hours of workshop material from two full-day sessions into five sessions of two hours each. Sessions were conducted one week apart from each other. The time and location of the intervention were adjusted to accommodate each participant’s personal schedule. The modified module used in the current study also included removal of content deemed inappropriate for the context of the research. This was done because John T. Blackledge’s module (2004) was intended for a group of parents of children with ASD who were distressed. In the current study; however, the module was customized for each individual. Table 1 is a brief description of the content of the intervention program.

Table I. Intervention Program

Session	Aim
1st Session <i>Creative hopelessness</i>	Review thoughts and negative feelings caused by having and caring for a child with ASD that the participant is trying to control (avoided/eliminated/unwanted). Identify control strategy that the participant has been attempting as a form of experiential avoidance of painful thoughts and feelings. Normalize intentions to control thoughts and feelings as a result of suffering, but inciting awareness that their attempts to control their thoughts and feelings thus far have been making them feel pressured. Introduce the idea that by trying to control their unpleasant thoughts and feelings they might make their situation worse.
2nd Session <i>Cognitive defusion</i>	- Help the participant realize that there is a gap between thoughts and the self, so they can identify when the self is too close to their thoughts. - Give exercises to help the participant simplify their thoughts and be able to experience relative truths.
3rd Session <i>Emotional willingness</i>	Increase the participant’s awareness about the concept of acceptance or willingness to clarify the idea that painful feelings or emotions can be

	accepted and that extra pain happens when we believe the evaluation we have made.
4th Session <i>Emotional willingness</i>	Continue the process of increasing the participant’s awareness of the concept of acceptance and willingness to clarify the idea that painful feelings or emotions can be accepted by training the participant to face the things that are making them feel uncomfortable as well as by giving them the chance to forgive themselves.
5th Session <i>Emotional willingness</i>	Train the participant to experience accepting unpleasant experiences and ask the participant to find values they consider important so that they can take on the goal of holding on to each value.

Results

The course of the intervention went smoothly and according to plan. Not many changes happened during the process. The following are the results of the intervention:

Table II. Pre-Test and Post-Test Scores as Measured by the *Modified Caregiver Strain Index*

Name ^a	Desi	Sita	Fani	Nia
Pre-test	19	15	11	18
Post-test	18	9	5	13

*not the real name

Desi’s MCSI scores decreased by 1 point, from 19 to 18, after all sessions were attended. Desi’s level of caregiver strain was generally high at the beginning of the program; after attending her sessions, her strain decreased although not by a statistically significant amount. Qualitatively, Desi stated that she had experienced a positive change. She admitted that she used to have migraines at least once a month, but about seven weeks after attending the intervention, she reported that she no longer had them. She also reported that she was not as easily angered as before. At the end of the intervention, although her child still frustrated her often, she was better able to deal with him calmly. Even if she became angry, the intensity of her anger was not as great as before.

The more Desi realized that she needed to provide maximum care for her child, the more she realized that there were things she could no longer do after she found out about her child’s autism. This made her feel restricted. Moreover, the fact that both her parents are smokers and that they often thwart her efforts to control her child’s diet has made Desi feel that she, more than ever, needs to do some adjustments in her caregiving.

Additionally, although Desi felt that the expense of providing care for her child was one of the main causes of her strain, she reported that, after the intervention, she was able to accept and perceive the situation more positively. More specifically, she felt more confident that there would always be sustenance for her child. The more her condition improved, the fewer tantrums

her child had, and the less often she had to ask her husband to take their child out, where they would usually buy snacks and other things. The fewer snacks her child consumed, the less likely he was to stay up late due to consuming sugar or milk. This pattern explains the decrease in her strain scores as measured by the MCSI.

Sita's MCSI score decreased by 6 points from 15 to 9. Her level of caregiver strain changed by such a degree that she is now categorized as having normal levels of caregiver strain. Qualitatively, Sita reported that she experienced a positive change in that, when things do not happen according to her standards or expectations, she felt that she was better able to accept the situation and consequently better able to figure out a solution to the problem.

After completing the program, Sita believed that she was able to be more patient and accepting of situations. She was able to believe that there would someday be time for her to get what she wanted. The intervention program made her feel that she could be calmer and better able to control her emotions and to deal with unpleasant situations.

Sita also felt that her ability to be calmer had positively influenced her relationship with her partner. Furthermore, she also felt closer to her child, because she used to be angry a lot and knew that her children were afraid of her.

Fani's MCSI scores decreased by 13 points from 18 to 5. Qualitatively, after completing the program, Fani felt that her emotional responses were no longer as explosive as before. Moreover, Fani felt that she was better able to identify what she wanted. Fani also felt that she knew better how to manage her emotional responses after completing the program. She was also better able to accept the current situation rather than spending her time worrying about things that may not happen.

Nia's MCSI scores decreased by 5 points from 18 to 13. Qualitatively, after completing the program, Nia felt that she had become more patient with regard to facing the situation at hand. Additionally, Nia felt that she was better able to identify her emotions. Nia is now better able to accept the fact that she is living at her aunt's home, and that therefore she cannot equate her standards with her aunt's, uncle's, and cousin's standards. She is better able to accept the condition that not everything can happen according to the standards she has set.

Moreover, Nia now feels better able to consider the values she identified at the beginning of the intervention and to use them as the basis of her actions. In the middle of the intervention, Nia also reported that she was able to sleep more easily at night compared to before, as a result of practicing basic mindfulness.

After the intervention, Nia felt that, although not all of her problems were resolved, she was able to perceive her burdens as lighter than before. She felt better able to identify the right path to follow. Nia saw a change in herself in that she became more motivated to deal with the

problem in front of her even though she knows there will be other things to think about for the next step.

Discussion and Conclusion

After receiving ACT, all four participants reported changes in the levels of caregiver strain they experienced, quantitatively as well as qualitatively. Moreover, all four participants also admitted that they felt calmer and were better able to make peace with unpleasant situations after they attended the sessions. During this study, the researcher was able to lead the interventions according to plan without any significant obstacles. Furthermore, participants in the study were able to attend all training sessions and understand the rationale behind ACT techniques.

All participants showed a decrease in their level of caregiver strain. Only one participant still experienced a high level of caregiver strain after the program. This may be due to several factors affecting quantitative data measurement. The use of the Likert scale could have made it difficult for this participant to give an accurate response to the statement because she found it difficult to rate herself.

This variation in the degree to which caregiver strain was decreased by the program may also have been caused by factors that influence caregiver strain such as the severity of each child's condition and the family's levels of income and social support. Desi felt that her son's non-verbal condition, his dependency, tantrum frequency, and flat and delayed display of emotions often escalated her emotions. The huge amount of money that she had to spend on her child's care was also one of the sources of her caregiver strain. Desi also felt that she only received social support from her husband. All of these factors likely contributed to the fact that her level of caregiver strain was still relatively high at the end of the intervention.

On the other hand, our qualitative analysis shows that ACT effectively reduced the caregiver strain experienced by participants in the current study. This finding supports the findings of previous studies indicating that ACT is an effective intervention in the clinical setting and can be successfully applied in various contexts such as depression, OCD, workplace stress, chronic pain, anxiety, PTSD, anorexia, addictive substance abuse, and even psychosis (Harris, 2006). In general, all four participants felt that they were calmer and less burdened and had a new perspective on their problems.

In general, ACT provides individuals with the opportunity to change their perspective on their feelings, thoughts, sensations, and other aspects they feel have been a burden in their lives. This change helps participants spend less energy and effort on attempting to resist or run away from things that make them feel uncomfortable, on the grounds that, since these things will occur again, they might as well learn to live with it. The hope is that participants can harness their energy to accomplish more meaningful and productive activities instead.

In several of our participants we observed a change in the intensity of their emotions when they talked about unpleasant situations. This intensity gradually decreased by the end of the intervention. This change occurred as the goal of ACT was slowly achieved for each participant. Participants come to see that their unpleasant experiences are temporary, so they tend to be better able to accept those experiences lightly. According to Hayes, Pistorello, and Levin (2012), a change in behavior occurs when people are involved in the current process of the intervention, and does not affect the changes that will happen in the future. In this intervention, such changes started to become evident in the fourth session, once participants had gone through the process of creative hopelessness, defusion, and mindfulness.

Desi attempted quite high levels of control strategy in the first session. This is a common response. According to Hayes, Strosahl, and Wilson (2003), therapists need to exert great effort in the first session to help the participant accept unpleasant past experiences. This is due to the high levels of experiential avoidance practiced by the participants as a means of dealing with uncomfortable feelings. Great length or duration of experiential avoidance causes them to find it difficult to open themselves and to want to experience uncomfortable feelings. In the cognitive defusion process, participants may realize that they can let intrusive thoughts go on their own. This is then followed up with learning about mindfulness, where they can learn how to accept themselves without judgment. Desi and Sita felt that the basic mindfulness method was the most helpful practice. This practice also helped them to identify their feelings so that their feelings would not fall further. For Sita, the practice of walking in silence also had a similar effect.

The process they experienced is in keeping with Barnard and Curry's explanation which states that mindfulness plays a part in the process of modifying cognitive patterns to become more positive (2011). Harris (2009) also stated that mindfulness can help individuals to change their relationships with intrusive thoughts, feelings, memories, and sensations. By changing these relationships, they can accept these components without getting further involved. With the change of perspective on their situations, at least for Desi and Sita, comes a decrease in their levels of caregiver strain.

In the fourth session, the training from the point of view of the observer was given, where participants were asked to be an observer of various aspects of their own life. Fani found this technique quite difficult because she found it hard to focus on the instructions. This exercise is the core of the ACT process and relates to people's spiritual side, whereas the exercises offered prior to this aim to prepare the individual to engage in this exercise optimally (Hayes, Strosahl, & Wilson, 2003). Difficulties in doing this exercise are mainly influenced by the participant's unreadiness or insufficient practice time on previous exercises.

The results of this study show that the implementation of ACT yielded benefits for four mothers with regard to their daily caregiving tasks on behalf of their children with ASD. The main benefit experienced was a decrease in their levels of caregiver strain. Decreased caregiver strain allows

individuals to function more optimally. From this intervention, participants can learn to accept unpleasant experiences and practice effective measures to achieve a more meaningful life.

The limitations of this study include the very short research period, which restricted the implementation of ACT techniques. Participants may not implement ACT techniques optimally when faced with unpleasant experiences if they do not get sufficient time to practice (Hayes, Strosahl, & Wilson, 2003). Participants have to practice ACT techniques at least 5-10 minutes daily so that the techniques can become a habit. The limited time also hindered the researcher from probing about each participant's experience with her family and her relationship with her own parents. Furthermore, we were unable to do follow-up sessions which would have enabled us to evaluate the participants' condition after the intervention and any after-effects they may have experienced.

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