

## A Support Program For Mothers As Caregivers Of Children With Disabilities In Indonesia

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### **Abstract**

*As primary caregivers of children with disabilities, mothers in Javanese society play a significant role in nurturing a child's independence. However, the families often blame mothers when giving birth to children with disabilities. Preliminary data showed that mothers with children with disabilities tend to have a high sense of guilt upon their children's conditions and lack knowledge of supporting child growth. The mothers also have lack support from their spouses and families. These situations make mothers experience mental and physical exhaustion, chronic stress, irritability, and lack of confidence, which leads to ineffective parenting strategies. The program's purpose is to equip caregivers with knowledge of stress management and effective parenting strategies for children with disabilities.*

**Keywords:** Caregiver children with disabilities, psychoeducation, counseling group

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### **I. INTRODUCTION**

Several studies have reported that caregivers of children with disabilities often experience a wide range of psychological problems. It includes high levels of stress, fatigue, anxiety, depression, Stigma, and discrimination often formed by traditional beliefs and poverty [1-5]. The limitations experienced by children with disabilities cause them to depend more on parents as caregivers than other children without disability issues. The heavy dependence of children with disabilities creates stressors for their parents as caregivers [6]. Caregivers also struggle to combine their caring and economic activities, which causes a low quality of mental health. These can result in poorer caregiver quality of life than caregivers of non-disabled children and have a negative impact on parenting strategies [2]. On the other hand, most families with children with disabilities live in rural areas and have low levels of education and lower economic status. They also have limited access to information and various negative labels in their children with disabilities [7]. Negative labels that appear, for example, children are considered unable to be independent, always have to get help from the surrounding environment [8], and become a burden on the family.

These negative labels from the community cause a psychological effect on parents, making them feel ashamed of the child's conditions [9]. In addition, the mothers become significant figures in the life of children with disabilities. Most children with disabilities are cared for and nurtured by their mothers. In the Indonesian context, the gender construction makes women have responsibilities in nurturing their children, so the mothers seem to struggle alone in caring for their children with disabilities. Mothers are always blamed for the conditions of the child. The disabilities experienced by children are considered as mothers' incompetence in caring for their pregnancy [10]. Sometimes, this was exacerbated by the common absence of their husbands. These conditions cause mothers to experience mental distress and physical fatigue in caring for their children. They have a low level of psychological well-being [9]. Based on the results of an initial interview with the Chairperson of the Disability Family Forum "PINILIH" in Yogyakarta, it is known that parents having children with disabilities have feelings of guilt over their children's conditions. It causes excessive presumption, loss of confidence, feeling confused and embarrassed. Then, these conditions make them secluded. Because of Stigma and presumptions on individuals with disabilities, these individuals are outcasts, so they have a low status in the communities. There are two external and internal problems experienced by villagers with disabilities in the

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Sedayu subdistrict. Internal problems include low independence and confidence, while external problems come from families to the surrounding communities, namely the lack of social support provided to individuals with disabilities.

Although caregivers have a vital role in the growth and development of children with disabilities, no intervention programs have been found that have attempted to relieve the psychological burdens of mothers and enhance their knowledge of effective parenting strategies in the Pinilih Forum. A caregiver must have good mental health and skills in dealing with stress and an adequate understanding of educating and nurturing children with disabilities. Therefore, it is essential to empower mothers as caregivers of children with disabilities to have effective parenting strategies in building a child's independence. A support program for caregivers of children with disabilities can improve caregivers' wellbeing [11]. The support program can increase understanding regarding child's difficulties, positive attitudes towards their children, and feelings of hope[11]. The support program for caregivers of children with disabilities can be a training and counseling program aiming to open a safe environment to share feelings and increase caregivers' skills in managing their own emotions and parenting children with disabilities[12]. This study shows the implementation of a community intervention program that aims to improve caregivers' wellbeing and knowledge of parenting children with disabilities.

## II. METHOD

The intervention model was an online counseling and psychoeducation group. An online counseling group aimed to provide a space for mothers to share their experiences as caregivers and feelings. Psychoeducation aimed to share knowledge in managing stress and parenting strategies of children with disabilities. It included the knowledge and skills in building children's independence by considering the characteristics and levels of child disability. All such activities can be described in detail in Table 1 below;

**Table 1.** Intervention Activities in *Caregivers of Children with Disabilities*

Activity	Purpose
Online counseling	1. Opening up the space to share stories and release negative emotions 2. Building acceptance and optimism over the condition of children with disabilities
Psychoeducation	1. Providing information about the characteristics of child development with various disability issues experienced 2. Providing information about stress in childcare and its management strategies 3. Providing information about how to nurture children following the characteristics of disabilities owned in order to be able to be independent in carrying out their daily activities

The program was carried out through the following stages of activity:

### 1. Preparation Stage

At this stage, coordination is carried out with team members to brainstorm the general theme of the intervention and the division of labor. The targeted partner also provided input on intervention methods and program materials.

### 2. Field Assessment Stage

The assessment stage was conducted through in-depth interviews and observations with family members with disabilities and stakeholders in Sedayu Subdistrict. The assessment explores the problems experienced by caregivers of children with disabilities, for example parenting issues, and its contributing factors.

### 3. Formulation of the Intervention Manuals

Activities at this stage were formulating themes of psychoeducation and its strategies. The members of Pinilih Forum were also involved in discussing the relevant themes and the strategies in delivering the themes.

### 4. Recruitment and Selection of Participants

5. At this stage, information regarding the program was given to forum members. All members were offered to join the program voluntarily as participants. The criteria of participants who can be involved in the intervention program are as follows;

- a. A caregiver who has a child with a disability. A single mother is more preferred
- b. Living with people with disabilities/ having intense daily interactions with children with disabilities,
- c. At least 18 years old

Those members of the forum who are interested are encouraged to contact the team member for further information regarding the activities, risks, and benefits.

#### 6. Intervention Stage

At this stage, counseling and psychoeducation were begun. Facilitators of the program implemented the intervention manuals

### III. RESULTS AND DISCUSSIONS

The psychoeducation was conducted online on June 9, 2021, collaborating with Sultan Idris University of Education, Malaysia. There were 20 participants from the Pinilih Forum who attended the program. The themes of psychoeducation were designed to equip mothers as participants with the knowledge and skills in managing stress and increasing resilience. The themes presented were as follows;

- Building self-strength to strengthen others
- Introduction to Neo-Cognitive Behavioral *Therapy*
- Stress Management,
- Tips for thinking positively and living happily
- Stress and Culture,
- Resilience and Hope,
- The characteristics of children with disabilities and skills in developing a child's independence

Psychoeducation is one training method. It enhances human capacities and knowledge since a person's ability to perform a job is limited by a lack of knowledge or skill. It bridges that gap by delivering the required instructions[13].

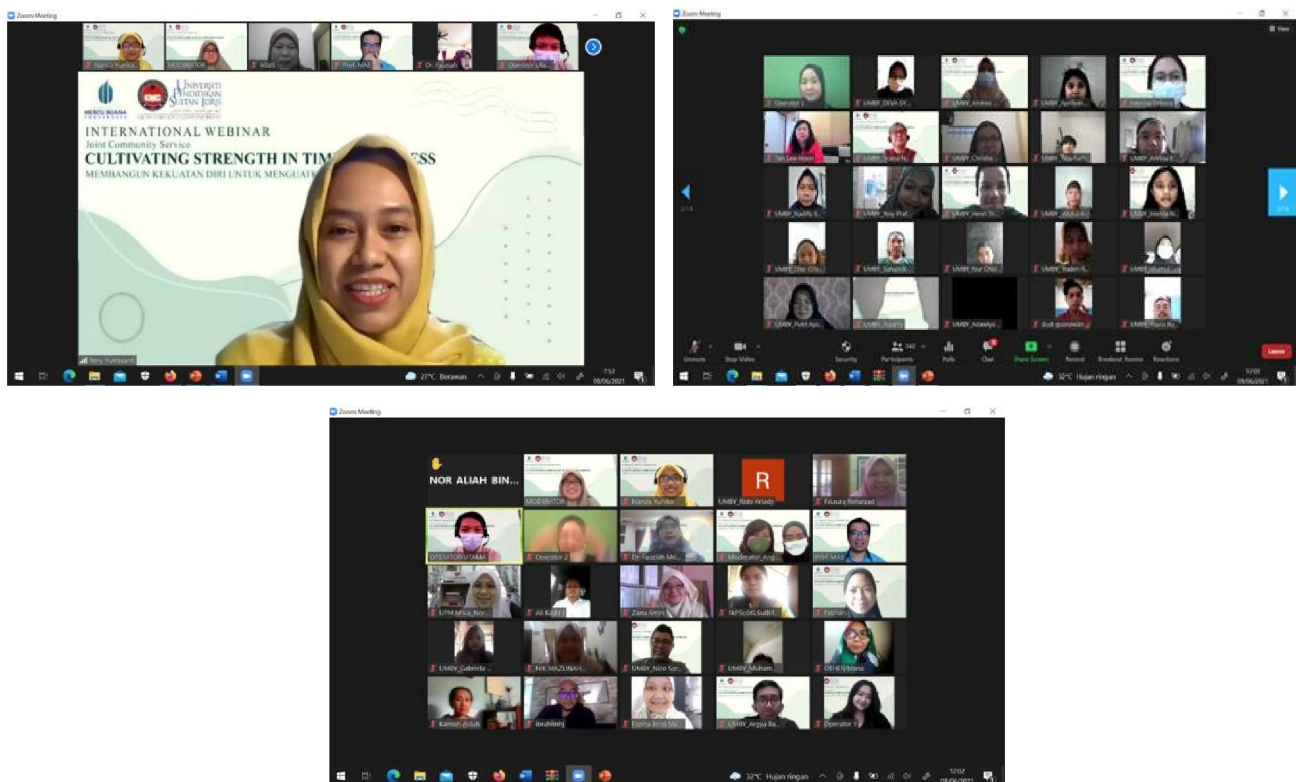
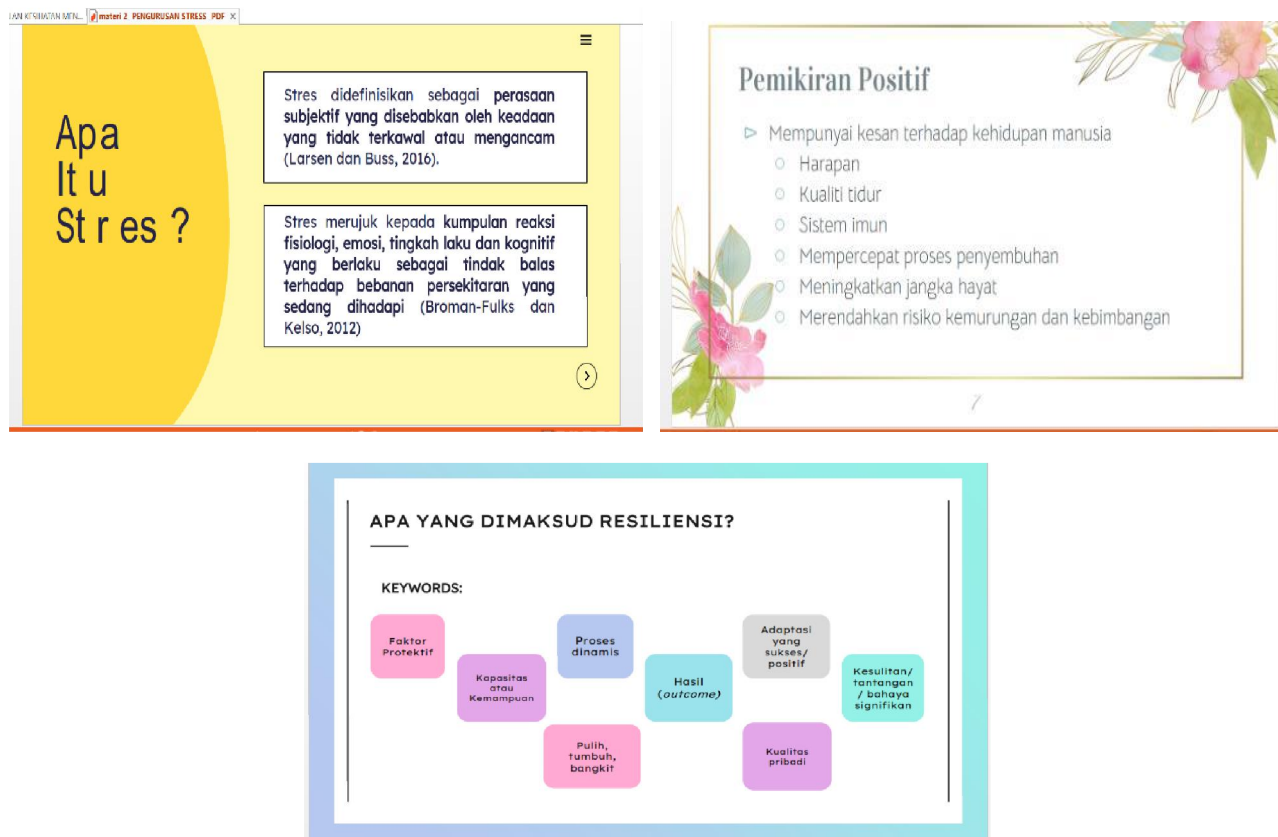


Fig 1. One of the Facilitators and Participants

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**Fig 2.** Resilience and Managing Stress

On July 17 and 24, 2021, online group counseling was conducted using zoom and google meet apps. 16 Pinilih Members joined the activities. Ten members are caregivers of children with special needs, while six are children with disabilities who have entered adolescence. Problems shared by caregivers were fatigue in caring for their children with disabilities and difficulty accepting children's conditions. Problems identified in children with disabilities were relationships with parents. The parents become less warm to understand the limitations experienced by children. The participants with disabilities expressed sadness and frustrations of their relationships with the families, particularly the mothers. Mothers often push too hard the participants to be independent in doing daily activities as an average child does. It seems that the mothers can not accept the limited conditions of their children.

It is similar to Onder and Gulay (2010) that stated higher rejection levels were determined among the parents of children with mental disabilities than parents of children with typical development. The disability issues act as a prominent factor in affecting parental acceptance-rejection behaviors. On the other hand, mothers as caregivers also expressed their psychological fatigue and hopelessness in caring for children with disabilities. Sometimes they expect their children to be like normal children. These findings are similar to a previous study that reported that mothers of children with disabilities often experience parenting stress, fatigue, anger, and frustration in managing their child's condition [14]. Therefore, group counseling sessions sought to establish a safe space to share their stories of exhaustion and despair over their child's condition by exploring their emotions and thoughts and encouraging other participants to express empathy and supports. The group counseling acts as a support network and a sounding board. Group members help other members develop specific ideas for improving a challenging life situation and hold them accountable [15]. At the end of the sessions, facilitators presented the characteristics of children with disabilities and skills in nurturing and developing a child's independence.

#### IV. CONCLUSIONS

A support program for mothers as caregivers of children with disabilities was a combination of group counseling and psychoeducation. The group counseling attempted to provide a safe space for mothers to share feelings and experiences and support each other participants. Psychoeducation consisted of seven themes: Building self-strength to strengthen others, Introduction to Neo-Cognitive Behavioral Therapy, Stress Management, Tips for thinking positively and living happily, Stress and Culture, Resilience and Hope, the characteristics of children with disabilities and skills in developing a child's independence. All activity was conducted online through zoom and google meet apps. It is expected that mothers can apply information and knowledge shared during the program, particularly in managing challenging situations with children with disabilities. Hence, children's independence is well developed.

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