The Effect of Family Psychoeducation Therapy on Stress of Families with Intellectual Disability Children at Special School

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ABSTRACT
This study aims to determine the effect of family psychoeducation on parent stress caring for intellectual disability children. The study used a quasi-experimental pre-post-test design with a control group. The sample included 60 mothers with mentally retarded children, who were selected using purposive sampling technique to participate in nursing intervention and family psychoeducation therapy, with 30 mothers in the control group, and 30 in the intervention group. The criteria of sampling included parents or primary family caregivers who care for intellectual disability children and schools in SLB-C Depok city, take direct care and live in one house with children with intellectual disability, and read and write and communicate well. The questionnaire consisted of respondent demographic data and the family stress scale (Z=0.715 on the stress scale). To analyse the data, t-test dependent tests were use because all data were normally distributed. The results showed that nursing intervention and family psychoeducation therapy can reduce parents' stress level in caring for intellectual disability children (p-value < 0.005). The combination of nursing intervention and FPE had a great impact on mother capability to face their stress.

KEYWORDS
Family psychoeducation
Intellectual disability
Quasi-experimental
Demographic data
Nursing intervention

Graphical Abstract
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Introduction
Mental disorder and challenging behaviour management in psychological and environmental terms is superior to the use of psychotropic medications and is suggested as a first- or second-line treatment in most cases. There is little but growing research supporting the use of therapeutic treatments for mental illness in people with intellectual disabilities. In the treatment of mood, anxiety disorders and obsessive-compulsive disorders, there is increasing evidence for the effectiveness of cognitive behaviour therapy and mindfulness. Other psychotherapies may also be successful in some patients with mild to moderate intellectual disability, including dialectic behaviour therapy to treat personality disorders [1,2]. No specific pharmacological therapy for cognitive dysfunction in developing children or adults with MR/ID is available. Once administered, drugs are aimed at particular medical comorbid diseases or behavioural disorders. Researchers have been interested in the development of nootropic drugs that may positively alter cognitive processes. Medicinal drugs commonly prescribed for dementia, such as inhibitors of acetylcholinesterase, are not accepted for MR/ID therapy and clinical trials have not been performed in children. Intellectual disability is a state characterized by a complete weakening of the mental and intellectual state resulting in a person’s inability to adapt [3]. Intellectual disability is difficult to recognize until mid-childhood [4]. It has been found that the highest incidence occurred in school-age children with a peak age of between 10 to 14 years. Globally, 1-3% of the world’s population is visually impaired. Based on the research of Ministry of Health survey in Indonesia in 2013, the number of intellectual disability children in Indonesia was about 30,460 children. The proportion of people with intellectual disability in the age group of 24-59 months is 0.14% and ranks third-most in the number of children with disabilities after the blind and visually impaired [5]. The condition of children with disabilities that are not in accordance with the wishes of parents turns the children to be the source of stress [6,7]. Families with intellectual disability children experience a variety of problems such as lack of family well-being, serious health problems, lack of material support, and living in poverty [8]. For families, this kind of situation has an impact on a psychosocial problem such as stress. Stress in the family is a situation where the family experiences inability and loses function in the family that arises from caring for intellectual disability children [9]. Based on the theory of stress and coping models, stress is a complex thing that influences humans and the environment [10,11]. Stress can cause maladaptive attitudes, depression, anxiety, decreased ability to control daily activities, and decreased physical function such as cardiovascular problems. Suppose the stress experienced by the mother with intellectual disability children cannot be controlled and lasts for a long time. In that case, it will be a big problem and have a negative impact on the development of the child. In addition, the stress experienced by mothers also has a major effect on negative parenting behaviour and child abuse [12]. Mothers who experience stress are very likely to abuse their children.

Having intellectual disability children requires families to be able to adapt in order to survive and continue the growth of the family. Family adaptation can run optimally if supported by an adaptive family coping strategy skill so that stress levels in caring for intellectual disability children can be handled [13–15]. The provision of therapy by professionals can help improve family coping ability in overcoming problems experienced in caring for children [16]. One therapy that can be given to reduce stress problems experienced by parents is Family Psychoeducation Therapy (FPE) [17,18]. The use of FPE to overcome stress problems in parents who care for intellectual disability children has not been sufficiently studied, so this study aimed to find out the influence, nursing therapy, and psychoeducation family on stress levels in parents who have children with intellectual disabilities.
Material and methods

Design
The design of this research was a quasi-experimental pre-post-test with a control group design. The interventions used in this study were nursing intervention in the control group and nursing and psychoeducation actions for family families in the intervention group to find out the influence of family psychoeducation on family stress.

Sample
This study used a purposive sampling technique. Purposive sampling is a sample selection technique by choosing a sample according to certain criteria. The criteria of samples included parents or primary family caregivers who care for intellectual disability children and schools in SLB-C Depok city, take direct care and live in one house with children with intellectual disability, able to read and write and communicate well. Based on the calculation of samples, the sample results obtained in this study were 30 mothers in the control group and mother in the intervention group.

Data Collection
To collect data, a questionnaire consisting of respondent demographic data, family stress from [19], namely the Parent Stress Scale (Z=0.715 on the stress scale) was used. The intervention group was given usual care and family psychoeducation. In contrast, the control group was given normal care only. All the data were normally distributed. Bivariate analysis was used to examine the effect of family psychoeducation therapy on family stress in caring for children with intellectual disability using paired t-test.

Intervention
Researchers provide interventions in both groups. The control group received the nursing intervention, and the intervention group received the nursing intervention and family psychoeducation therapy. Both the control and intervention consisted of 4 small groups with 7-8 people per group. In the control group, the given nursing intervention was carried out for 30 minutes and only received nursing intervention once. The nursing intervention provided included education about stress and coping mechanisms for families with intellectual disabilities children. In the control group, researchers provided nursing intervention for 30 minutes and at the next meeting the researcher gave a family psychoeducation therapy, carried out for 120 minutes. Family psychoeducation therapy was administered three times over three weeks. Family psychoeducation therapy was carried out as many as three sessions with three meetings for each group. Family psychoeducation therapy was carried out for six days for all intervention groups. Each day the therapy was given to two groups only. Intervention activities were carried out at school while the mother was waiting for the child at school.

In the first session, the researchers conducted an assessment of maternal problems in caring for children, assessing children's health problems, and providing health education on the concept of intellectual disability. From the assessment conducted, it was found that mothers faced several problems in caring for their children. Of the four groups that were given family psychoeducation therapy, the problems expressed by the mother were almost the same, including complaining of dizziness, lack of rest due to child care, inability to control emotions, stress in dealing with children, children's attitudes (tantrums, difficulty remembering, mood swings, motor problems) and problems in the family economy. Then each mother chose the problem she wanted to solve and together with the researcher discussed how to handle the problem. After that, the mother asked to reveal the health problems experienced by the child. The problems of the children most often expressed by mothers were about the child's mood that was difficult to overcome, the ability of the child and slow development, tantrums, and the condition of the child who was difficult to
adapt, especially with reference to eating meals with family members. Furthermore, the first session began with the provision of health education about the concept of intellectual disability children.

In the second session, the researchers provided health education about the concept of stress and stress management. In assessing the stress experienced by mothers, researchers found that mothers were stress due to economic difficulty and daily activities due to lack of rest. After that, researchers did stress management intervention and exercises with mothers, deep breath therapy, and progressive muscle relaxation therapy. After finishing the activity, the mother reported that her body condition becomes relaxed. The mother enthusiastically took part in the training and committed to practicing it again at home.

In the third session, the researcher was given training about the management of burden. A support system was applied that began with assessing the burden faced by the mother, both objective and subjective burden. After the assessment, the mother complained of experiencing a heavy burden in caring for her child, such as fatigue, worry about the child’s future, and financial difficulties. After discussing how to deal with the burden, the activity was continued by identifying the support system in the family and evaluating the activities carried out.

**Ethical considerations**

This research passed the ethics test conducted by the Ethics Committee of the Nursing Research Committee of the Faculty of Nursing, Universitas Indonesia, as evidenced by a certificate passing the research ethics review number No.165/UN2.F12.D/HKP.02.04/2018

**Result and Discussion**

Based on Table 1, the average age of parents of intellectual disability children was 41 years, with the youngest age of 34 years and the oldest age of 52 years. The average age of intellectual disability children was 13 years old with a young age of 9 years, and the oldest age is 19 years. An analysis of the child's parental equality based on the age of the parent and the age of the child found that the intervention and control group was equivalent (p-value > 0.05).

| Variable      | Groups       | N  | Mean | Median | SD  | SE   | Min-Max | 95% CI       | p-value |
|---------------|--------------|----|------|--------|-----|------|---------|--------------|---------|
| Age of Parents| Intervention | 30 | 41.70| 42.00  | 6.04| 1.14 | 36-50   | 2.58-2.86   | 0.92    |
|               | Control      | 30 | 41.57| 39.50  | 4.18| 0.73 | 34-52   | 2.59-2.86   |         |
|               | Total        | 60 | 41.56| 40.50  | 5.09| 0.87 | 34-52   | 2.58-2.86   |         |
| Age of Children| Intervention| 30 | 13.53| 13.50  | 2.063| 0.377| 9-19    | 12.76-14.30| 0.20    |
|                | Control      | 30 | 13.07| 13.00  | 2.461| 0.267| 10-16   | 12.52-13.61|         |
|              | Total        | 60 | 26.57| 27.00  | 4.524| 0.644| 9-19    | 12.52-14.30|         |

Based on Table 2, the education of the parents of intellectual disability children was mostly senior high school as many as 31 people. Most of the parents of intellectual disability children were housewives, 47 people; the most were low-income families, 45 people, and most were married, 47 people. Meanwhile, for the classification of intellectual disability, most children experienced mild intellectual disability, 34 people. Equality analysis at the level of education, occupation, income, socioeconomic status, marital status and the classification of intellectual disability of children was equivalent (p value> 0.05). Gender showed no difference.
Table 2: Analysis of equality and distribution of characteristics of parents and children with intellectual disability at Special Schools in 2018 (n = 60)

| No. | Characteristic                  | Intervention | Control | Total | p value |
|-----|---------------------------------|--------------|---------|-------|---------|
|     |                                 | n | %   | n | % | n | % |
| 1   | Parents                         |   |       |   |     |       |     |
|     | Mother                          | 30 | 50% | 30 | 50% | 60 | 100 |
| 2   | Educational level               |   |       |   |     |       |     |
|     | Elementary School               | 4 | 13,3 | 4 | 13,3 | 8 | 13,3 |
|     | Junior High School              | 5 | 16,7 | 14 | 46,7 | 19 | 31,7 |
|     | Senior High School              | 19 | 63,3 | 12 | 40,0 | 31 | 51,7 |
|     | Graduated                       | 2 | 6,7 | 0 | 0 | 2 | 3,3 |
| 3   | Professions                     |   |       |   |     |       |     |
|     | Have a job                      | 3 | 10 | 10 | 83,3 | 13 | 21,7 |
|     | House wife                      | 27 | 90 | 20 | 66,7 | 47 | 78,3 |
| 4   | Economic level                  |   |       |   |     |       |     |
|     | Middle                          | 10 | 33,3 | 5 | 16,7 | 15 | 25 |
|     | Low                             | 20 | 66,7 | 25 | 83,3 | 45 | 75 |
| 5   | Marital status                  |   |       |   |     |       |     |
|     | Married                         | 25 | 60,0 | 22 | 73,3 | 47 | 78,3 |
|     | Widowed                         | 5 | 40,0 | 8 | 26,7 | 13 | 21,7 |
| 6   | Intellectual disability level   |   |       |   |     |       |     |
|     | Mild                            | 18 | 53,3 | 16 | 53,3 | 34 | 56,7 |
|     | Moderate                        | 12 | 46,7 | 14 | 46,7 | 26 | 43,3 |

The level of stress of parents in caring for children with intellectual disability using the Parent Stress Scale with a range of values was 18-72. The greater value of stress indicated that parents were experiencing severe stress. Table 3 shows that the average of parents who cared for intellectual disability children was 49.48 with a median value of 48.50. From these results, the researchers divided the two categories of parental stress into the high-stress category if the mean test results were above or equal to the median value and the mild stress category if the mean value was below the median value. It can be concluded that parents of mentally retarded children experienced high stress because the mean value was the same as the median value of the test results. The equivalence analysis for the stress levels of parents caring for parents of mentally retarded children shows that the stress levels of parents were not equal (p-value <0.05).

Table 3: Distribution of Average and Equality of Family Stress before Nursing and Family Psychoeducation Group Therapy for Parents of Children with Intellectual Disabilities in Special Schools in 2018 (n = 60)

| Variable | Group | n | Mean Before Nursing Intervention | Median | SD | SE | Min-Max | 95% CI | p value |
|----------|-------|---|----------------------------------|--------|----|----|---------|-------|---------|
| Stress Keluarga | Interventio n | 30 | 47,50 | 48,00 | 5,35 | 0,97 | 36-57 | 45,50-49,50 | 0.01 |
|           | control | 30 | 51,47 | 52,00 | 6,19 | 1,13 | 37-59 | 49,15-53,78 |       |
| Total     |       | 60 | 49,48 | 49,50 | 6,08 | 0,78 | 36-59 | 47,91-51,05 |       |

Based on Table 4, family stress decreased from 51.50 to 49.20 after nursing intervention was given in the control group and indicated a decrease in family stress levels. Based on the results of the analysis, there was no meaningful decrease in parental stress after getting nursing intervention in the control group (p-value >0.05).

Table 4: Changes in family stress intellectual disability children in control group after getting nursing intervention in Special Schools in 2018 (n=30)

| Variable | n | Mean Before Nursing Intervention | Mean After Nursing Intervention | Mean Diff after Nursing Intervention | Mean Diff after Self-training | Mean Diff | p-value |
|----------|---|----------------------------------|---------------------------------|-------------------------------------|-------------------------------|-----------|---------|
| Parent stress | 30 | 51.47 | 51.50 | 0.03 | 49.20 | 2.27 | 0.950 |
Based on Table 5, family stress decreased from 47.50 to 41.00 with a difference of 6.50 after nursing intervention and family psychoeducation therapy in the intervention group. Based on the analysis results, there was a significant decrease in stress scores after the administration of nursing intervention and family psychoeducation therapy (p-value < 0.05).

**Table 5**: Changes in family stress of intellectual disability children in intervention group after getting nursing intervention and family psychoeducation therapy (FPE) in SLB-C in 2018 (n=30)

| Variable   | n  | Mean Before Nursing Intervention | Mean After Nursing Intervention | Mean diff after Nursing Intervention | Mean after FPE | Mean diff after FPE | p-value |
|------------|----|----------------------------------|---------------------------------|--------------------------------------|----------------|---------------------|---------|
| Parent Stress | 30 | 47.50                            | 45.00                           | 2.5                                  | 41.00          | 6.50                | 0.00    |

The stress of parents caring for intellectual disability children based on the study results was 49.48. The results of this study proved that the stress experienced by parents exceeded half of the total score. This indicates that the stress felt by parents showed a high score where the score was at least 37 and a maximum of 57 with the median of statistical test results of 48. The results of this study are in line with the results of previous research [20], stating that parents who cared for visually impaired children experience high psychic stress. Based on the results of the analysis of stress questionnaires consisting of two dimensions, namely pleasure dimensions or positive dimensions (emotional management, self-acceptance, and self-development) and strain dimensions or negative dimensions (the source of problems, costs, and limitations), the stress experienced by the mother was dominated by the negative dimensions where stress occurred because the mother felt not maximal in providing care to the child. The mother reported that she was worried about her son's future with frequent complaints. The results of this study are in line with those of a previous study [21], which reported that parents who had children with visual impairment experienced stress, anxiety, and felt guilty for the child. As a result, mothers often neglect their own needs because they have to care for, supervise, and meet the needs of children [10]. Another difficulty that causes stress in mothers in this study was in dealing with children's behaviour, which resulted in the mother's facing short of time for rest, especially at night. Compulsive behaviour of children and tantrums can harm the child and the environment. This condition makes the mother worried about letting the child interact alone without supervision. The mothers who have children with intellectual disabilities have insufficient time of sleep. The condition, if it lasts a long time, can lead to a decrease in the degree of health, quality of life, and the risk of depression [22]. The lower the level of well-being, acceptance, and satisfaction in living life as a parent, the greater the chance of mothers experiencing stress in parenting.

Interaction between parents, especially mothers and children, in fulfilling complex needs and intensive care is the cause of stress experienced by mothers [23]. It is said the stress that occurs in the family creates conflict for the recipient of the role [24]. So, being a parent of an intellectual disability child is a factor that causes stress due to a change of role in the family [25,26]. It has been reported that family psychoeducation therapy is a family therapy with the aim of improving family welfare, knowledge of the disease, treatment, prevention of recurrence, improving coping strategies, and reducing family stress levels [27]. The act of nursing by providing health education about ineffective family coping mechanisms consisting of handling in the form of problem identification, discussing the choice of efforts that can be used in solving problems, expressing feelings for each other after using the
suitcase, and discussing the alternatives of coping used, is a nursing intervention given so that the mother can apply an adaptive coping mechanism by focusing on problem-solving [28–30]. According to previous research [10], using a good coping mechanism and focusing on problems is very beneficial to reduce the degree of stress experienced by mothers in caring for intellectual disability children. After obtaining psychoeducation family therapy, the stress of the mother in caring for an intellectual disability child experienced a significant decrease (p-value < 0.05). The results of this study are similar to those of previous research [31-34], stating that family psychoeducation therapy is significantly able to reduce the stress of parents in parenting children who have a positive impact on the interaction between mother and child. The provision of family psychoeducation therapy after being given nursing intervention turned out to provide a greater increase compared with performing the nursing intervention. Also, improving the family's ability to make decisions about what family members experience will be the basis for them in assisting the care or recovery of family members' condition.

**Conclusion**

Psychoeducation given to families in this study was psychoeducation conducted in groups. As revealed previously, where the implementation of therapy in groups can trigger the spirit and curiosity of the condition of the child in each member of the group, establish familiarity, support each other and motivate members to be open to each other about the condition of the child. The implementation of therapy carried out in groups indirectly improved the ability of coping mothers, because through group therapy all perceived problems would be discussed then spontaneously caused reactions to support each other. As far as getting strong information from health workers and support from friends is concerned, a relative is an important factor that is often neglected in the family in building an effective family coping mechanism. In line with previous research on family psychoeducation in groups, psychoeducation conducted in groups made it easier for respondents to express feelings and support each other. The limitation of this study was the small sample size with very close interventions between sessions. It is recommended that future research hold two meetings for each session so that the implementation of the intervention can be maximized. In addition, the time between the post-test and the last session was too close so we could not get to know to what extent the intervention given to the mother could affect conditions in the family. Further research can be carried out within the scope of the intact family.

**Acknowledgment**

Authors would like to acknowledge Indonesian Endowment fund for education (LPDP) for research funding assistance.

**Authors’ contributions**

All authors contributed toward data analysis, drafting and revising the paper and agreed to be responsible for all the aspects of this work.

**Conflict of Interest**

We have no conflicts of interest to disclose.

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