



## DEPRESSION IN PARENTS OF CHILDREN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

### DEPRESIJA KOD RODITELJA DJECE S INTELEKTUALNIM I RAZVOJNIM TEŠKOĆAMA

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#### ABSTRACT

The conducted research aimed to examine the level of depression among parents of children with intellectual and developmental disabilities. The sample included 100 participants evenly divided into two groups: 50 parents of children with intellectual disabilities and 50 parents of children with autism spectrum disorder. To assess the level of depression, the Depression subscale from the Depression, Anxiety, and Stress Scale (DASS) was used. For testing the hypothesis, nonparametric statistics were applied since the results deviated from a normal distribution. To test differences in dichotomous variables such as the child's gender, age, type of developmental disability, and the parent's gender, the Mann-Whitney U test was used. For testing differences in polytomous variables (the number of children in the family), the Kruskal-Wallis H test was used. To examine the relationships between variables, Spearman's correlation coefficient (Spearman's rho) was used. The study found that the sociodemographic characteristics (age, gender, and type of disability) of children with intellectual and developmental disabilities do not affect the level of depression in parents. Characteristics of the family (number of children) and parents (gender) do not affect the occurrence of depression in parents. The research also determined that there is no statistically significant relationship between the level of depression and satisfaction with types of support, as the results showed no correlation. Although there are no statistically significant differences, there are individual differences in relation to the observed variables, which indicates the need for further examination in future research.

**Key words:** intellectual and developmental disabilities, depression, parents, support.

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## SAŽETAK

Provedeno istraživanje imalo je za cilj ispitati nivo depresije kod roditelja djece sa intelektualnim i razvojnim teškoćama. Uzorak ispitanika je obuhvatio 100 ispitanika ravnomjerno raspoređenih u dvije skupine, 50 roditelja djece sa intelektualnim teškoćama i 50 roditelja djece sa poremećajem autističnog spektra. Za ispitivanje nivoa depresije primijenjena je subskala Depresija iz Skale za procjenu nivoa depresije, anksioznosti i stresa (DASS). S obzirom da rezultati odstupaju od normalne distribucije za testiranje hipoteza koristila se neparametrijska statistika. Za testiranje razlika dihotomnih varijabli kao što su spol djece, dob djece, vrsta teškoće u razvoju, spol roditelja korišten je Mann-Whitney U test, dok je za testiranje razlika politomnih varijabli (broj djece u porodici) korišten Kruskal-Wallis H test. Za ispitivanje povezanosti među varijablama korišten je Spearmanov koeficijent korelacije (Spearman's rho). Istraživanjem je utvrđeno da sociodemografska obilježja (dob, spol i vrsta teškoće) djece sa intelektualnim i razvojnim teškoćama ne utiču na nivo depresije kod roditelja. Nisu utvrđene statistički značajne razlike u odnosu na karakteristike porodice (broj djece) i roditelja (spol). Istraživanjem je također utvrđeno da ne postoji statistički značajna povezanost nivoa depresije sa zadovoljstvom vidovima podrške jer su rezultati pokazali da ne postoji korelacija. Iako ne postoje statistički značajne razlike, prisutne su individualne razlike u odnosu na posmatrane varijable, što ukazuje na potrebu daljeg ispitivanja u budućim istraživanjima.

**Ključne riječi:** intelektualne i razvojne teškoće, depresija, roditelji, podrška

## INTRODUCTION

Mood disorders or affective disorders are disorders whose emotional difficulties include frequent mood swings resulting from a loss of control over one's emotions (Begić, 2011). Among the most significant mood swings in quantitative terms is depressive mood. It is a negative affective state characterized by low mood, feelings of sadness, helplessness, listlessness, hopelessness, apathy, and depression (Begić, 2011). Depressive disorders are the most common of all psychiatric disorders. The prevalence ranges from 5-17% and they are 2-2.5 times more severe in women than in men (Begić, 2011; Dhar & Barton, 2016). Depression is accompanied by a range of cognitive and biological symptoms, including low mood, anhedonia, negative cognitions, lack of energy, and appetite disorders, and in the worst case, it can manifest itself with suicidal thoughts and a psychotic state (Dhar & Barton, 2016). Mechanisms of depression include genetic predisposition, monoamine deficiency, circadian rhythm abnormalities, hypercortisolemia, increased levels of inflammatory cytokines, and oxidative stress (Salim, 2014). Depression and frequent episodes of depressed mood can also negatively affect physical health. Changes in circadian rhythm are observed, evident through later or earlier awakenings, insomnia, or excessive sleeping (APA, 2013).

Depression can be caused by a variety of factors, one of which is raising a child with a developmental disability. Due to greater exposure to stress and higher levels of anxiety, parents of chronically ill children are at greater risk for developing depression than parents of healthy children (Dykens & Lambert 2013). Research shows that the occurrence of depression is influenced by the type and severity of the child's developmental disability, and parents of

children with intellectual disabilities and autism exhibit the highest levels of depression ( Millaku & Kraja-Bardhi, 2023). Parents of children with intellectual disabilities face a number of unique challenges that can significantly affect their emotional and mental health. In addition to their usual parenting responsibilities, these parents often have to balance intensive care, the child's complex medical needs, interaction with the educational and health systems, and coping with social stigma and isolation. Numerous studies have confirmed that parents of children with intellectual and developmental disabilities are at increased risk of developing depressive symptoms compared to parents of typically developing children (Davis & Carter, 2008; Olsson & Hwang, 2001; Singer, 2006; Scherer, Verhey, & Kuper, 2019 ). A meta-analysis by Singer (2006) showed that 30-50% of parents of children with intellectual and developmental disabilities show depressive symptoms, which is three to four times higher than in parents of children without disabilities. Olsson and Hwang (2001) report that about 40% of mothers and 20% of fathers of children with intellectual and developmental disabilities have significant depressive symptoms, while in parents of typically developing children the prevalence is about 10-15%. Scherer, Verhey, and Kuper (2019) found in their meta-study that 31% of parents of children with intellectual and developmental disabilities meet the criteria for diagnosing moderate depression compared to 7% of parents of children without developmental disabilities.

Depression in parents of children with intellectual and developmental disabilities not only affects their personal well-being, but can also negatively affect the emotional and social development of their child, as well as family dynamics as a whole (Hastings, 2002). Risk factors for depression are numerous, and for parents of children with intellectual and developmental disabilities, the main stressors include intensive care, medical and therapeutic requirements, financial difficulties, and behavioral problems of children, which further increase emotional stress (Hastings, 2002; Davis & Carter, 2008). The impact of stress is also strong on mental health, so depression and anxiety often occur (Rejani & Ting, 2015). Social isolation and lack of support further worsen parents' mental health (Boyd, 2002). Mothers are at higher risk for depression, which is related to their primary caregiving role and the greater number of hours spent caring for the child ( Azem et al., 2013; Cohrs & Leslie, 2017; Chouhan, Singh, & Kumar, 2016; Davis & Carter, 2008; Dardas & Ahmad, 2014; Ricci et al., 2017 ). Parental depression can negatively affect the quality of parenting and children's development, creating a vicious cycle of stress and behavioral problems (Hastings, 2002; Singer, 2006). Social support, availability of psychological services and stability of material conditions are key protective factors that reduce the risk of depression in parents (Boyd, 2002; Singer, 2006).

Parents of children with intellectual and developmental disabilities in our country also face numerous challenges in caring for and raising a child with intellectual and developmental disabilities, so the presence of depression is to be expected in them. In our country, some key issues regarding support for families and children with developmental disabilities in general, such as early intervention, the right to obtain medical and assistive devices, personal assistance, etc., have not been systematically and legally resolved, and a much higher level of depression among parents is to be expected. On the other hand, in our country, research very rarely deals with this issue. In accordance with all of the above, the main goal of the research

was to determine the level of depression among parents of children with intellectual and developmental disabilities. It was also intended to determine whether there are differences in the expression of depression in parents in relation to factors on the part of the child (age, gender and type of disability), in relation to the characteristics of the family (number of children) and the parents (gender). The connection between depression and satisfaction with forms of support was also examined.

## **MATERIALS AND METHODS**

### **Sample of participants**

The sample of parents included 100 respondents, of which 50 were parents of children with intellectual disabilities and 50 were parents of children with autism spectrum disorder, of both sexes. The criteria for inclusion in the sample of parents of children with intellectual and developmental disabilities were: the child's age from 6-16 years, a diagnosis of intellectual disabilities and/or autism spectrum disorder, attendance at educational institutions and the parents' interest in participating in the research. When it comes to the gender of the children, 66% are male, while 34% are female. In terms of the age of the children, 62% of the children are aged 6-11 years, while 38% of the children are aged 12-16. In terms of the gender of the parents, the sample consisted of 50% mothers and 50% fathers. In terms of age, 8% of parents are between 20 and 30 years old, 33% of parents are between 30 and 40 years old, while 16% of parents are between 50 and 60 years old. The largest number of parents is between 40 and 50 years old, or 43%. When it comes to the employment status of parents, 63% are permanently employed, 8% are part-time employed, while 29% are unemployed. In terms of qualification level, the largest number of parents have a secondary education, or 62%, followed by a university degree, or 22%. 7% of parents have a higher education, while 5% have a master's degree, and only two parents have a doctorate, or 2%. In terms of the number of children in the family, out of the total number of parents, 53% have two children, 20% have one child, while 27% of parents have three or more children in the family. The sample of parents was collected from several towns in the Herzegovina-Neretva Canton (Mostar, Stolac, Konjic, Jablanica, Čitluk).

### **Measuring instruments**

Depression in parents of children with intellectual and developmental disabilities was examined with the Depression subscale from the Depression, Anxiety and Stress Scale (DASS-S, SH Lovibond & PF Lovibond, 1995). The Depression subscale has 14 statements, and the respondent is asked to evaluate each statement with regard to how often, in the last seven days, he experienced certain feelings of depression (eg, I was listless and depressed). The depression scale consists of statements describing low self-esteem, low mood and lack of motivation. The depression scale assesses dysphoria, hopelessness, devaluation of life, self-esteem, lack of interest/involvement, anhedonia, and inertia. The degree of depression on the scale was verified as: 0 - 9 normal depression score, 10 - 13 mild depression, 14 - 20 moderate depression, 21 - 27 severe depression, 28 and above very severe depression. In addition to the DASS scale, a General Questionnaire was used to collect general data about the parents and the child.

## Data processing methods

Statistical data processing was done in the statistical package SPSS 21.0 for Windows. The normality of the distribution of results on the total score of the DASS-S test was determined by the Kolmogorov-Smirnov test. The results showed that the Kolmogorov-Smirnov test is statistically significant ( $KS = 0.160$ ,  $df = 100$ ,  $p = 0.000$ ) and that the results deviate from the normal distribution. Non-parametric statistics were used for hypothesis testing. The Mann-Whitney U test was used to test differences in dichotomous variables such as gender of children, age of children, type of developmental disability, gender of parents, while Kruskal-Wallis H test was used to test differences in polytomous variables (number of children in the family). Speraman's correlation coefficient (Spearman  $s$  rho) was used to examine the relationship between variables.'

## RESULTS AND DISCUSSION

### Level of depression in parents of children with intellectual and developmental disabilities

One of the goals of the study was to examine the level of depression in parents of children with intellectual and developmental disabilities, and the results are given in Table 1.

**Table 1.** Depression in parents of children with intellectual and developmental disabilities

|            | AS   | SD   | Minimum | Maximum | Range |
|------------|------|------|---------|---------|-------|
| Depression | 7,61 | 8,60 | 0,00    | 31,00   | 31,00 |

The results show that parents of children with intellectual and developmental disabilities achieve a mean score of  $AS = 7,61$ , which corresponds to a normal depression score (Table 1). The values of the standard deviation  $SD = 8,60$  show that within the group there are significant individual differences in the level of depression, which is confirmed by the minimum score of 0 and the maximum score of 31. In order to get a clearer picture of the level of depression in parents, Table 2 shows the frequencies of depression in parents of children with intellectual and developmental disabilities in relation to the degree of expression. .

**Table 2.** Frequency of depression in parents of children with intellectual and developmental disabilities in relation to the degree of severity

| Depression              | N   | %     |
|-------------------------|-----|-------|
| Normal depression score | 62  | 62,0  |
| Mild depression         | 17  | 17,0  |
| Moderate depression     | 12  | 12,0  |
| Severe depression       | 6   | 6,0   |
| Very severe depression  | 3   | 3,0   |
| Total                   | 100 | 100,0 |

The results shown in Table 2 show that the majority of parents of children with intellectual and developmental disabilities, or 62% of parents, achieve a normal depression score, which means that they do not have significant symptoms of depression. However, a significant percentage of parents (38%) show the presence of depression of varying degrees of severity, from mild to very severe. The largest proportion of parents with depressive symptoms are those with mild (17%) and moderate (12%) forms of depression, while severe depression is present in 6% of parents and very severe depression in 3%. Normal depression scores do not necessarily mean that parents do not have certain emotional difficulties. Parents may still experience everyday challenges associated with caring for a child that do not necessarily result in severe depression but can cause fatigue, stress and less serious symptoms that are not necessarily covered by standard measurement instruments. The results indicate the importance of recognizing and providing support to parents who show signs of depression, even in milder forms, in order to prevent the condition from worsening. The finding that 38% of parents show varying degrees of depression aligns with global research. For example, Scherer et al. (2019) reported 31% of parents of children with developmental disabilities meet criteria for moderate depression, while Xia et al. (2023) found 35,5% at risk. Azeem et al. (2013) reported 40% of mothers and 31% of fathers met depression criteria. Other studies show even higher rates: Olsson & Hwang (2001) found 45–50% among mothers, Alsaad et al. (2023) reported 85.1%, and Alibekova et al. (2022) found 53,7% among parents of children with autism. Sharma et al. (2021) reported 66,3% of mothers and 35,4% of fathers with symptoms, while Chouhan et al. (2016) and Chou et al. (2010) highlighted strong links between child disability and maternal depressive symptoms. Firat et al. (2002) found high depression rates in Turkish mothers of children with autism (72.5%) and intellectual disabilities (44.7%).

### **Differences in the level of depression in parents of children with intellectual and developmental disabilities in relation to the characteristics of the children**

The aim of the research was also to examine differences in the level of depression among parents of children with intellectual and developmental disabilities in relation to children's characteristics such as gender, age and type of developmental disability (Table 3).

**Table 3.** Differences in the level of depression among parents of children with intellectual and developmental disabilities in relation to the children's characteristics

| Variables          |                           | N  | Mean Rank | Sum of Ranks | U        | Z      | p     |
|--------------------|---------------------------|----|-----------|--------------|----------|--------|-------|
| Child's gender     | Male                      | 66 | 49,02     | 3235,50      | 1024,500 | -0,724 | 0,469 |
|                    | Female                    | 34 | 53,37     | 1814,50      |          |        |       |
| Age                | 6-11 years                | 62 | 47,37     | 2937,00      | 984,000  | -1,406 | 0,160 |
|                    | 12-16 years old           | 38 | 55,61     | 2113,00      |          |        |       |
| Type of difficulty | Autism spectrum           | 50 | 47,93     | 2396,50      | 1121,500 | -0,904 | 0,366 |
|                    | Intellectual difficulties | 50 | 53,07     | 2653,50      |          |        |       |

The results of the Mann-Whitney U test (Table 3) show that there are no statistically significant differences in the expression of depression in parents of children with intellectual

and developmental disabilities in relation to the gender of the children ( $U = 1024,500$ ,  $Z = -0,724$ ,  $p = 0,469$ ), although parents of female children achieve a higher  $MR = 53,37$  compared to parents of male children  $MR = 49,02$ . Alsaad et al. (2023) also do not find a relationship between depression in parents of children with intellectual and developmental disabilities and the gender of the children.

Table 3 shows that the results of the Mann-Whitney U test show that there is no statistically significant difference in the expression of depression among parents of children with intellectual and developmental disabilities in relation to the age of the children ( $U = 984,000$ ,  $Z = -1,406$ ,  $p = 0,160$ ). Parents whose children are older (from 12 to 16 years old) ( $MR = 55,61$ ) have a slightly higher mean rank than parents whose children are younger (from 6 to 11 years old) ( $MR = 47,37$ ). Alibekova et al. (2022) found that a child's age does not affect parental depression, while Pocinho and Fernandes (2018) reported that parents of older children with developmental disabilities are more prone to depression. This research also suggests higher depression levels among parents of older children, though the difference isn't statistically significant. These findings highlight the need for further study, as concerns about children's future, independence, and transitions to adulthood may increase parental stress. However, results remain inconsistent; for example, Alsaad et al. (2023) found the highest depression rates in parents of children aged 6–10.

The results of the Mann Whitney U test (Table 3) show that there is no statistically significant difference in the expression of depression among parents of children with intellectual and developmental disabilities in relation to the type of child's disability ( $U = 1121,500$ ,  $Z = -0,904$ ,  $p = 0,366$ ). Parents of children with intellectual disabilities ( $MR = 53,07$ ) show a slightly higher mean rank compared to parents of children with autism spectrum disorders ( $MR = 47,93$ ). These results align with Manuel et al. (2003), who found that the child's condition (mild or severe) didn't impact maternal depression, highlighting the need for holistic, individualized family support. However, other studies (e.g., Lee et al., 2017; Freedman et al., 2012; Rejani & Ting, 2015) suggest that parents of children with autism experience higher depression levels compared to parents of children with other disabilities or no disabilities. Rejani and Ting (2015) also noted greater risks of depression, anxiety, and marital conflict among these parents. Additionally, several studies (Das et al., 2017; Eikeseth et al., 2015; Scherer et al., 2019) found that the severity of autism symptoms is directly linked to parental stress and depression.

### **Differences in the level of depression among parents of children with intellectual and developmental disabilities in relation to family and parent characteristics**

Differences in new depression in parents of children with intellectual and developmental disabilities and in relation to family characteristics, i.e. the number of children in the family, are given in Table 4.

**Table 4.** Differences in the level of depression among parents of children with intellectual and developmental disabilities in relation to the number of children in the family

| Number of children in the family | N  | Mean Rank | Kruskal-Wallis H | df | p     |
|----------------------------------|----|-----------|------------------|----|-------|
| One                              | 20 | 48,10     | 4,978            | 2  | 0,083 |
| Two                              | 53 | 46,13     |                  |    |       |
| Three and more                   | 27 | 60,85     |                  |    |       |

The results of the Kruskal-Wallis H test show that parents with three or more children achieve the highest mean rank of 60,85, then parents with one child 48.10 and the lowest parents with two children 46,13. The results of the Kruskal-Wallis H test show that the observed differences are not statistically significant and that there is no difference in the manifestation of depression among parents of children with intellectual and developmental disabilities in relation to the number of children in the family ( $H(2) = 4,978$ ,  $p = 0,083$ ). These results show that the number of children isn't a key factor in parental emotional state, but families with three or more children may face higher depression risk due to increased responsibilities. Alsaad et al. (2023) also found higher depression rates in larger families. While more children can sometimes offer protective support (Gialla & Gavidia-Payne, 2006), they can also increase parental stress (Lindström et al., 2011). Families with only one child with disabilities may be especially vulnerable due to less internal support (Hastings, 2003). Overall, factors like family relationships, finances, and social support play a bigger role than family size alone (Plant & Sanders, 2007).

**Table 5.** shows the results relating to differences in the level of depression in parents of children with intellectual and developmental disabilities in relation to the characteristics of the parents, i.e. the gender of the parents.

**Table 5.** Differences in the level of depression in parents of children with intellectual and developmental disabilities in relation to the gender of the parents

| Gender | N  | Mean Rank | Sum of Ranks | U        | Z      | p     |
|--------|----|-----------|--------------|----------|--------|-------|
| Male   | 50 | 51,53     | 2576,50      | 1198,500 | -0,362 | 0,717 |
| Female | 50 | 49,47     | 2473,50      |          |        |       |

The results of the Mann-Whitney U test (Table 5) show that fathers have a slightly higher mean rank of 51,53 compared to mothers, 49,47, but that the observed difference is not statistically significant ( $U = 1198, 500$ ,  $Z = -0,362$ ,  $p = 0,717$ ). These results indicate that the emotional burden caused by caring for a child with intellectual and developmental disabilities affects both mothers and fathers equally. The results indicate that regardless of differences in traditional gender roles and expectations, parents of children with intellectual and developmental disabilities experience similar levels of emotional stress and psychological burden. This may mean that the challenges of caring for a child with disabilities exceed the influence of gender differences in the parental role. The results highlight the importance of

providing support to both mothers and fathers through programs aimed at reducing stress, anxiety and depression. Differences in the expression of depression are not found between mothers and fathers in the research of Alibekov et al. (2022), while in other studies he finds that mothers show a greater tendency to depression (Azeem et al., 2013; Olsson & Hwang, 2001). And if the gender of parents plays an important role in shaping the risk of depression in parents of children with intellectual and developmental disabilities (Singer, 2006; Dunn et al., 2001), this risk strongly depends on the roles within the family (Hastings et al., 2005), the availability of social support (O'Brien, 2001) and the coping strategies used by parents (Gray, 2003; Pottie & Ingram, 2008). For future interventions, it is important to recognize the specific needs of both mothers and fathers in order to provide targeted support and reduce the risk of depression in this population.

### **The relationship between depression levels in parents of children with intellectual and developmental disabilities and satisfaction with forms of support**

The aim of the research was to examine the relationship between the level of depression in parents of children with intellectual and developmental disabilities and satisfaction with the types of support that parents receive, and the results are shown in Table 6.

**Table 6.** Relationship between levels of depression in parents of children with intellectual and developmental disabilities and satisfaction with forms of support

| Variable         | Spearman 's rho              | Depression | Satisfaction with forms of support |
|------------------|------------------------------|------------|------------------------------------|
| Satisfaction     | with Correlation Coefficient | 0,008      | 1,000                              |
| forms of support | p                            | 0,934      | .                                  |
|                  | N                            | 100        | 100                                |

The results of Spearman's correlation coefficient (Table 6) show that there is no statistically significant relationship between depression and satisfaction with types of support among parents of children with intellectual and developmental disabilities ( $\rho = 0,008$ ,  $n = 100$ ,  $p = 0,934$ ). These results indicate that satisfaction with support, although important, is not a key factor that directly affects the level of depression in parents. Depression occurs as a result of a combination of factors, including personal characteristics, social circumstances, financial difficulties and perception of one's own situation, not just satisfaction with support. Parents can receive support that formally exists, but is not necessarily in accordance with their specific needs or expectations, which can reduce its impact on their emotional state. This result does not diminish the importance of providing support, but suggests that support must be adapted to the specific needs of parents in order to have a greater impact on their emotional well-being. Further research is recommended that could include additional factors, such as the quality of support, the type of help provided, and individual differences among parents, in order to better understand how support can affect the reduction of depression in this population. Contrary to the results of this research, previous research indicates that satisfaction with support is an important protective factor against the development of depression in parents of children with intellectual and developmental disabilities. Singer

(2006) in a meta-analysis emphasizes that mothers who are dissatisfied with social support have higher levels of depressive symptoms. Hastings and Brown (2002) emphasize the importance of parental self-efficacy related to feelings of support and control. Pottie and Ingram (2008) show that perceived satisfaction with support has a stronger impact on depression than the objective amount of help. Smith, Greenberg and Seltzer (2008) find that sources of support are different for mothers (friends, family) and fathers (marital relationship). Future interventions should focus on increasing the availability and quality of support and strengthening parental feelings of satisfaction and control.

## CONCLUSION

The study showed that parents of children with intellectual and developmental disabilities have a normal level of depression on average, but almost 38% of them are affected by depression of varying severity, from mild to very severe. No statistically significant difference was observed in the level of depression in relation to the child's gender, age of the child, type of disability, number of children in the family, and gender of the parents. However, parents of older children and those with a larger number of children in the family show a tendency towards higher levels of depression, which indicates possible additional stressors associated with these factors. The results confirm previous studies that highlight the increased risk of depression in parents of children with disabilities, emphasizing the need for continuous support. Based on the results of the study, it is recommended to establish a system for early recognition of depressive symptoms in parents of children with intellectual and developmental disabilities, in order to provide them with timely and adequate psychological support. Special attention should be paid to parents with more severe forms of depression through specialized programs that include psychotherapy and group forms of assistance. Support should be adapted to the individual needs of families, taking into account the complexity of their life circumstances, especially families with a large number of children, who are exposed to additional stress. Also, it is important to include both parents in assistance programs, because working together can make it easier to face challenges. In addition to psychological support, it is necessary to provide adequate social and institutional assistance in order to reduce the overall burden of parental responsibilities. Finally, it is necessary to continue with research that will examine in more detail the risk factors and mechanisms of depression in these parents, which will contribute to a better design of future interventions.

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