



INTERNATIONAL JOURNAL OF  
EDUCATION, PSYCHOLOGY  
AND COUNSELLING  
(IJEPC)

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PSYCHOLOGICAL DISTRESS AMONG PARENTS OF  
CHILDREN WITH SPECIAL NEEDS

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**Article Info:**

**Article history:**

Received date: 28.04.2022

Revised date: 15.05.2022

Accepted date: 16.06.2022

Published date: 28.06.2022

**To cite this document:**

Wahab, R., & Ramli, F. F. A. (2022). Psychological Distress Among Parents Of Children With Special Needs. *International Journal of Education, Psychology and Counseling*, 7 (46), 498-511.

DOI: 10.35631/IJEPC.746037

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**Abstract:**

Psychological distress referred to an emotional suffering state characterized by depression such as lost interest and hopelessness and anxiety symptoms such as felt tension and restlessness. Parents of children with special needs were likely to be at a higher risk of psychological distress since they might experience many challenges to raise the children. The long-term issues of children with physical-motor disorders and mental retardation and the need for continuous treatment, these parents would experience high levels of stress and frequently became depressed, frustrated, and disappointed with their children development This study aimed to identify the severity of psychological distress of the parents among special needs children and the relationship between demographic variables and parents' psychological distress among special needs children. A total of 224 parents with special needs children in Terengganu were involved. The psychological distress of parents was measured by using Kessler Psychological Distress Scale (K10). Results indicated 36.6% of parents were having severe distress, 21% were experiencing moderate distress and, 21.9% had mild distress. Parent's job status had indicated a positive significant correlation between severity of psychological distress ( $r = 0.148$ ,  $N = 224$ ,  $p < 0.05$ ). The other variables such as parent's age, parent's gender, child's age and diagnosis, parent's marital status, and parent's education level had shown no significant correlation between the severities of psychological distress. In conclusion, most parents were having psychological distress. Nevertheless, only the job status had demonstrated an impact on the psychological distress of parents.

**Keywords:**

Children With Special Needs, Disability, Parents, Psychological Distress, Job Status

## Introduction

The role of parents became more complicated when having special needs children despite the challenging milestone in parenthood (Jambekar et al., 2018). Parenting a child with special needs commonly went beyond natural parenting since they had to deal with various shifting criteria related to the individual needs of their children (Isa et al., 2016). Parents might feel mixed feelings when they knew that their children were disabled (Sen & Yurtsever, 2007). Raising these children with specific conditions such as autism, Attention Deficit hyperactive disorder (ADHA), and other disorders probably led parents to elevated psychological symptoms. In contrast to parenting normal developing children, parenting special needs children could lead to problems with family functioning, parenting distress, and fluctuating parenting styles (Masulani-mwale et al., 2018).

Disability in children might result in an emotional and social burden to the parents. They often experienced plenty of negative feelings, such as stress, anxiety, depression as they were much more fearful of their future and the future of their children, which could impact their health (Parameswari & Eljo, 2009). Besides, they were at high risk of having psychological distress compared to parents with normal children. Psychological distress was referred to an emotional suffering state characterized by depression and anxiety symptoms (Drapeau et al., 2012). The high levels of internalizing and externalizing concerns in children had indicated in contribution to the high degree of stress (Ricci et al., 2017). Since the parents bearded the bulk of the increasing daily care load for these children, they might raise the risk of extreme stress and, in some circumstances, depression (Kobayashi et al., 2012). Therefore, it was crucial to examine the extent of the psychological distress among parents with special needs children so that the solutions, interventions, and approaches implemented in these contexts to help and support the parents.

## Literature Review

### *Children With Special Needs*

Children with special needs could be known as children with neurodevelopmental disorders (NDD). NDD was a term utilized for a wide range of conditions such as Cerebral Palsy (CP), and genetic disorders that involved injuries to the brain, and other conditions that limited functional abilities such as vision, hearing, speech, behavior, motor, and cognition problems (Maridal et al., 2021). They were referred to as the children who required additional help and support from education, health, medical, and social-environmental services to improve their health, growth, learning, quality of life, engagement, and community inclusion beyond that needed by children generally (Jambekar et al., 2018). They commonly could not play, learn and perform activities they were supposed to do at their age since they could not use their physical, mental, and social abilities properly. Generally, this disability in children should be measured individually or combined from body functions and structures, developmental, cognitive, and affective (Sen & Yurtsever, 2007). Moreover, they usually experienced various hurdles in their first few years of life and prolonged into adulthood, such as critical health conditions, disruptive habits, and diagnostic tests putting the burden on the parents (Downey, 2016).

Special needs children had thought to be a burden to the family in psychological, physical, social, and economic status. Parents' life balance was crucial since it would influence the development of children. Caring for children with special needs could lead to the difficulty

between balancing the working life and providing attention to them (Bahry et al., 2019). Parents needed to balance the multiple roles with limited available resources that involved time and energy such as balancing between work and taking care of them where they were required to attend the children's appointments at the hospital. When they were unable to fulfill their responsibilities, they developed the guilty feeling for not playing well with the role of ideal parents (Angie et al., 2017). Parents also had to spend more time with the children by spending a lot of time taking care of their eating, hygiene, bathing, delivering therapeutic activities (Faramarzi, 2017). This was supported by previous study that stated parents needed to spend extra time supporting the children to eat, dress, walk, and perform another activity (Suriati et al., 2011).

### ***Financial***

Raising children with special needs had become increasingly expensive and arduous for parents. Food, special equipment, and medical costs for children had all become more expensive over time (Bahry et al., 2019). Parents needed to continually seek medical and additional treatment for their children that might cause a financial burden (Park & Kim, 2020). Over time, one of the parents would be the primary caretaker for their children in a constant, which might be resulting in a decrease in a function to work, thus reducing the parent's financial (Chen et al., 2020; Vonneilich et al., 2016). When compared to parents of usually developing children, parents of special needs children put in more work and even forewent career prospects to care for their children. When a family's financial status diminished, parents' anxiety increased, endangering their mental health (Ren et al., 2020).

Financial issues had been identified as a crucial indicator that impacted both stress and anxiety levels of parents of children with disabilities in numerous analyses conducted in the study. In addition to financial difficulties, the additional commitments for special needs children induced stress, which led to elevated levels of anxiety and depression among parents. These variables were discovered to cause an impact on self-confidence self-esteem, and, personal adaptability, and marital relationships. Financial constraints also influenced the severity of anxiety. It had shown that persons exposed to unfavorable societal views and people who cared for special needs children, while not being their parents, had higher levels of anxiety (Uskun & Gundogar, 2010).

### ***Social Support***

According to a research, social support was an essential element in lowering parental stress and improving their ability to manage with psychological issues. Unfortunately, parents of special needs children were frequently alienated from public and society's concern, despite the fact that good parental attitudes toward parenting special needs children were invariably associated with increased social support. These risk factors exacerbated psychological issues in parents of children with special needs (Chen et al., 2020). It was addressed in a study that lack of support from the surrounding had an impact on the worsening distress of the parents in the terms of feeling isolated, frustrated, and stigma (Leitch et al., 2019).

### ***Behaviour Issues***

The pronounced issue for parents was dealing with the misbehavior and emotional issues of special needs children and the pressure to rear such children (Chen et al., 2020; Totsika et al., 2014). Some special needs children were likely to display severe behavioural problems, and, in the meantime, this might exacerbate the psychological issue (Park & Kim, 2020).

Externalized behaviours of the children such as communication issues, poor social interactions and, oppositional defiant disorder were more prominent in special needs children than in ordinary children. Children with special needs such as autism might exhibit tantrums, frustration, and anxiety due to many factors such as when they were unable to go outside or not accustomed to following new rules. At the same time, they had difficulty communicating with their parents and solve problems on their own (Chen et al., 2020). The study revealed that behavioural problems in children could anticipate the possibility or alteration in the affective quality of parent-child interactions. Hence, parents must be exerted additional efforts during the parent-child interactions (Karst & van Hecke, 2012). As a result, parents must devote more time and resources to their children, thereby increasing parenting stress. Furthermore, when it was arduous to resolve recurring and restricted behavioural issues, parents were prone to be more decisive and control by using verbal or physical chastising, which might reduce the bonding and increases parent-child dysfunction. It merely not worsened the children's misbehaviours over time but also worsening parents' mental health problems (Chen et al., 2020).

### ***Psychology Issues***

The psychological issues that parents encountered might differ depending on nature, the severity of their children's disorder, and the sort of disability itself. Background research on the psychological health of parents of special children indicated that, relative to parents of ordinary children, parents of these children exhibited severe stress, restricted social relationships, and an extent of depression. In other words, taking into account the long-term issues of children with physical-motor disorders and mental retardation and the need for continuous treatment, these parents would experience high levels of stress and frequently became depressed, frustrated, and disappointed with their children development (Faramarzi, 2017).

Parents of children with autism reported to be substantially more depressed than the parents of children with a pervasive developmental disorder (PDD-NOS) (Rezendes & Scarpa, 2011). They also had been reported to have an extent of degrees of stress, anxiety, and depression compared to parents of typically developing children and children with other developmental problems (Vasilopoulou & Nisbet, 2016). Besides, Isa et al (2016) stated that these parents were reported to have high physical symptoms, anxiety, social instability, depressing attitudes, and stress compared to parents of children with Down syndrome.

The depressive symptoms also had been found in the mothers of children with ADHD due to their children's symptoms such as hyperactivity, inattentive and disruptive behaviour (Chi & Hinshaw, 2002). The negative feelings such as a feeling of despair, judgment, sorrow, guilt, helplessness, anger, depression, and frustration were common in the parents of ADHD children (Leitch et al., 2019). A study by Musa & Shafiee (2007) mentioned that parents of children with ADHD were having substantial psychological distress on the increase of anxiety, depressive, and distress levels due to the externalizing and internalizing behaviours of the children. Due to this circumstance, parents had reported having low self-confidence, self-esteem, and personal adaptation.

A comprehensive review of the literature on the impact of caregiving on the quality of life of parents of children with cerebral palsy stated that caretakers of children with CP had greater levels of stress, depression, and poor quality of life than parents of ordinary children. Inadequate self-efficacy of parenting skills and support systems, as well as children's behaviour

and cognitive difficulties, had all been discovered to increase stress and depression (Jambekar et al., 2018; Pousada et al., 2013). Raising children with cerebral palsy who had limitations in mobility was more physically challenging and psychologically demanding. Higher stress level and depressive moods had discovered in the mother of children with CP that experienced severe activity limitation. This psychological issue made them felt more challenging to manage the parenting and their children's problems. Their self-esteem was also affected due to the fluctuating feelings of self-worth triggering by the children's difficulties (Park & Kim, 2020). According to the previous study, mothers of children with CP had the highest severity of depression and psychological distress than children with other conditions. The reason for this was that most of the children with CP needed to move and go to school using wheelchairs and, the mothers had to carry their children and the wheelchairs while sending them to the school. In addition, some of the children were dependent on feeding. As a result, parents needed to stay in the school to feed their children (Ahmad Zam Zam et al., 2019).

Previous researches found the parents of special needs children such as children with intellectual disabilities (IDs), developmental delays and, physical and sensory impairments had more probability to exhibit signs of psychological distress or depressive symptoms, and, reduced well-being than parents of ordinary children (Kobayashi et al., 2012). According to the study, care and education requirements, social attitudes and judgments regarding disability, and ambiguity about the child's current and future status were crucial sources of anxiety and pressure for parents. Parents who had special needs children were more stressed, anxious, and had poorer self-confidence, stigma, self-esteem, and marital harmony than parents who did not have impaired children. It was critical to decreasing the anxiety that might cause adverse implications in parents' behavioural, cognitive and, emotional regulations. Parents who were distressed because their children were not being accepted by the community experienced significant anxiety and social support-seeking scores (Akturk & Aylaz, 2017). In short, the demands required in the caregiving of these children could cause maternal depression as well as negative consequences of the parenting experience (Park & Kim, 2020). This study was executed in order to identify the severity of psychological distress among parents of children with special needs and to identify the relationship between demographic variables and severity of psychological distress among parents of children with special needs.

## **Methodology**

### ***Materials and Methods***

This study applied the quantitative research method using a cross-sectional design through the administration of an online survey. The sample in this study was based on purposive sampling, which is based on the judgment of the targeted respondent that could offer the best-suited information to accomplish these study objectives.

The instrument used in this research was separated into two parts. Section one related to the demographics of the respondents, which included their children's age and diagnose, parent's gender and age, marital status, education level and occupation status. Section two consisted of The Kessler Psychological Distress Scale (K10) questionnaire which is a self-report measure that focused on questions about symptoms of anxiety and depression (Pereira et al., 2019). It was a well-established, highly useful psychological symptom measure noted for its ease of administration, reliability, high predictability, and high validity of factor and construct. Answer choices were based on a Likert-type 5-point scale ranging from 1 which was none of the time

to 5 which was all of the time. Responses were totaled to generate a total score that ranged from 10 to 50, with higher scores indicating more psychological distress (Easton et al., 2017). The K10 had indicated good psychometric properties from the results of the validity analyses that were 0.84 with 95% CI (0.81, 0.96). The reliability showed that the alpha coefficients of Cronbach for the control group and case group were 0.837 and 0.885, respectively (Tiong et al., 2018). The questionnaire had been carried out through google form and then distributed virtually on social media to the parents of children with special needs in Terengganu due to the outbreak of Covid-19. An online link was created to collect responses from the respondents.

### ***Method of Data Collection***

The process of collecting data began in late February 2021 and ended in July 2021. The Research Ethics Committee (REC) of the University Technology Mara had granted ethical approval. The data of participants have been collected by distributing the questionnaire virtually using social media as the outbreak of Covid-19 preventing to collect the data physically. The questionnaire consisted of the demographic form and The Kessler Psychological Distress Scale (K10) where it was created using the google form. The respondents that fulfilled the inclusion criteria would complete the questionnaire voluntarily.

### ***Population and Sample Size***

The participants in this study were Terengganu parents of children with special needs. According to the Ministry of Women, Family and Community Development (2020), the population size of special needs children in Terengganu was 950. The Raosoft Sample Size Calculator Online Software had used to compute the sample size. The margin error of the study had been decided with 5% and, the confidence level of 95% as indicated in many studies in health sciences. With a population size of 950 and response distribution of 50%, the total number of representative samples required for generalization was 274

### ***Participants***

The respondents that fulfilled the inclusion criteria completed the questionnaire voluntarily. A total of 265 responses were received, of which 224 were valid. The prerequisite criteria were that the participant were the parents of children with special needs aged from 6 to 12 years old and, the children had been registered as Person with Disabilities (PWD). The parents also must live together with their children with special needs and able to read and understand the English language to answer the questionnaire. non-parents or caregivers of children with special needs have been excluded to focus on the psychological distress of the parents.

### ***Data Analysis***

The Statistical Package for Social Sciences (SPSS 26), which focused on descriptive and inferential statistics, was deployed to evaluate the data acquired in this study. The descriptive analysis was used to identify the severity of psychological distress among parents of children with special needs. Meanwhile, Spearman correlation was conducted to identify the relationship between demographic variables and severity of psychological distress among parents of children with special needs.

### ***Results and Discussion***

Table 1 summarized the demographic data of the respondents. There were 97 (87.9%) female participants and 27 (12.1%) were male respondents. The parents' age had divided into four ranges. 7 (3.1%) parents ranged from 20 to 29 years old, and 129 (57.6%) parents were age

between 30 to 39 years old which indicated the highest frequency of respondents' age involved. Then, 79 (35.3%) parents were age from 40 to 49 years old and, another 9 (4.0%) were aged 50 years old and above. Most of the parents achieved a high level of education of 154 (68.8%) were accomplishing the tertiary education, followed by 49 (21.9%) parents who had a primary level of education and another 21 (9.4%) parents had achieved education at the secondary level. Also, 209 (93.3%) parents were in married status, 14 (6.3%) parents had divorced and, merely 1 (0.4%) parent was widowed. The result also indicated that 151 (67.4%) parents were still working, and 15 (6.7%) parents had already retired. Another 58 (25.9%) parents were not working.

For their children's diagnoses, 90 (40.2%) was the highest diagnosis of the children's parents in this study which was the Autism Spectrum Disorder (ASD), followed by 43 (19.2%) children with Attention-Deficit/Hyperactive Disorder, 33 (14.7%) for children with Cerebral Palsy, 30 (13.4%) for children with Learning Disabilities, 13 (5.8%) for children with multiple disabilities and another 15 (6.7%) children were coming from the other types of disabilities. 68 (30.4%) were children aged 6 years old that indicated the highest age of the respondents' children. Meanwhile, 12 (5.4%) came from children of 11 years old that showed the lowest frequency of the respondents' children.

**Table 1: Demographic Data of the Respondents.**

Demographic variable	Frequency (N)	Percent (%)
Parent's Age		
20 - 29 years old	7	3.1
30 – 39 years old	129	57.6
40 – 49 years old	79	35.3
50 years old and above	9	4.0
Parent's Gender		
Male	27	12.1
Female	97	87.9
Child's Diagnosis		
Attention-Deficit/Hyperactivity Disorder (ADHD)	43	19.2
Autism Spectrum Disorder	90	40.2
Cerebral Palsy	33	14.7
Learning Disabilities	30	13.4
Multiple Disabilities	13	5.8
Other disability	15	6.7
Child's Age		
6 years old	68	30.4
7 years old	30	13.4
8 years old	31	13.8
9 years old	28	12.5
10 years old	13	5.8
11 years old	12	5.4
12 years old	48	18.8

Parent's Education		
Primary	49	21.9
Secondary	21	9.4
Tertiary	154	68.8
Marital Status		
Married	209	93.3
Divorced	14	6.3
Widowed	1	0.4
Occupation Status		
Employed	151	67.4
Unemployed	58	25.9
Retired	15	6.7

According to the result of the K(10) questionnaire, the highest mean score from the questionnaire item was item 8 that was "About how often did you feel that everything is an effort?" with (M= 3.16, SD =1.019) was the score that indicated most of the respondents felt that everything they did was an effort. Meanwhile, the lowest mean score was item 3 which was "About how often did you feel so nervous that nothing could calm you down?" with (M =2.25, SD =0.958). It indicated that most respondents felt the least nervous feeling that nothing could calm them down. Table 2 below showed a clear picture of the mean and standard deviation on every question on the Kessler Psychological Distress Scale (K10).

**Table 2: A Mean and Standard Deviation of Kessler Psychological Distress Scale (K10)**

No.	Items	Mean	Std. Deviation
1.	About how often did you feel tired out for no good reason?	3.03	0.862
2.	About how often did you feel nervous?	2.67	0.907
3.	About how often did you feel so nervous that nothing could calm you down?	2.25	0.958
4.	About how often did you feel hopeless?	2.64	1.070
5.	About how often did you feel restless or fidgety?	2.69	0.975
6.	About how often did you feel so restless, you could not sit still?	2.37	1.007
7.	About how often did you feel depressed?	2.68	1.118
8.	About how often did you feel that everything is an effort?	3.16	1.019

9.	About how often did you feel so sad that nothing could cheer you up?	2.45	1.001
10.	About how often did you feel worthless?	2.43	1.106

According to the Kessler Psychological Distress Scale (K10) scoring criteria, a score between 20 to 24 indicated mild distress, 25 until 29 indicated moderate distress and 30 to 50 indicated severe distress. In this study, 82 (36.6%) parents had severe distress which means most parents in this study were having severe psychological distress. Meanwhile, 46 (20.5%) parents were likely to be well with the lowest result of severity in psychological distress. Moderate distress was scored at the second-highest of severity in psychological distress of 47 (21.10%) the parents indicated moderate distress while another 49 (21.9%) parents indicated mild distress. Table 3 represented the severity of psychological distress among parents of children with special needs.

**Table 3: The Frequency of Severity of Psychological Distress among Parents of Children with Special Needs**

Severity	Frequency (N)	Percent (%)
Likely to be well	46	20.5
Mild Distress	49	21.9
Moderate distress	47	21.0
Severe distress	82	36.6
Total	224	100

Spearman correlation coefficient analyses were performed to explore the relationship between the severity of psychological distress among parents of children with special needs and their demographic data coefficient since the Shapiro-Walk indicated the p-value of the severity of parent's psychological distress was 0.041 ( $p > 0.05$ ) while the p-value for parent's demographic data was 0.00 ( $p > 0.05$ ) which demonstrated the data was not normally distributed.

The results study reported that the severity of psychological distress was positively related to marital status ( $r = 0.23$ ,  $p < 0.05$ ) and job status ( $r = 0.148$ ,  $p < 0.05$ ). Meanwhile, the other variables which were parent's age ( $r = -0.084$ ,  $p < 0.05$ ), gender ( $r = -0.089$ ,  $p < 0.05$ ), children's age ( $r = -0.045$ ,  $p < 0.05$ ), and children's diagnosis ( $r = -0.127$ ,  $p < 0.05$ ), and parent's education level ( $r = -0.100$ ,  $p < 0.05$ ) was found to be negatively correlated to the severity of psychological distress among parents of children with special needs. Overall, only one correlation was revealed to be statistically significant that was between the severity of psychological distress and the parent's job status ( $r = 0.148$ ,  $N = 224$ ,  $p < 0.05$ ) with the significant values were  $p < 0.026$ . Therefore, there was a significant positive correlation between the parents' job status and the severity of their psychological distress. Table 4 indicated the correlation between the demographic data and the severity of psychological distress among parents of children with special needs.

**Table 4: Spearman Correlation Results between Severity of Psychological Distress and Demographic Data of Parents of Children with Special Needs.**

Demographic Variable		Severity of Psychological Distress
Parent's Age	Spearman	-.084
	Correlation	.208
	Sig. (2-tailed)	.224
	N	
Parent's Gender	Spearman	-.089
	Correlation	.183
	Sig. (2-tailed)	.224
	N	
Child's Diagnosis	Spearman	-.127
	Correlation	.058
	Sig. (2-tailed)	.224
	N	
Child's Age	Spearman	-.045
	Correlation	.503
	Sig. (2-tailed)	.224
	N	
Parent's Education	Spearman	-.100
	Correlation	.136
	Sig. (2-tailed)	.224
	N	
Marital Status	Spearman	0.23
	Correlation	0.735
	Sig. (2-tailed)	.224
	N	
Occupation Status	Spearman	0.148*
	Correlation	0.026
	Sig. (2-tailed)	.224
	N	

\*Correlations are significant at the  $p < .05$  level

#### ***Psychological Distress among Parents of Children with Special Needs***

This study discovered that most parents of children with special needs experienced psychological distress with a percentage of 79.5%. 36.6% of parents were having severe psychological distress that could be alarming to their mental health. Psychological distress was described as emotional suffering that could be either depressed mood or anxiety. There was a research that discovered the frequency of psychological distress among parents of children with intellectual disabilities and, the result showed high psychological distress of 41% of them were experiencing it. The high prevalence rate reported in this study indicated the extent of previously untreated psychological distress (Masulani-mwale et al., 2018). This study finding was congruent with the previous study that reported both mothers and fathers of children with developmental disabilities had considerably greater probabilities of being diagnosed with depression or another psychological issue (Marquis et al., 2020). One study found that parents that raised special needs children were at high risk for depression although its risk might not

be high compared to other studies (Aaron Resch et al., 2012). In another study, it stated that parents of children with developmental disabilities and mental issues had been documented to experience poor psychological well-being and greater degrees of depression, which included stress, sadness, and anxiety symptoms. It also revealed that parents of children with ADHD and developmental disabilities experienced distressed higher than parents of children with HIV, asthma, and parents of healthy children (Feizi et al., 2014).

A result in a study of parents with children with ADHD also showed that these parents experienced significant psychological distress due to the challenges in rearing the ADHD children that displayed about 63% of parents were having depressive symptoms. Moreover, parents of children with ADHD and associated comorbidities were exceedingly difficult to handle these children, and they eventually became distressed (Musa & Shafiee, 2007). At least one comorbidity was reported in 64% of ADHD children that might influence parent's distress (Leitch et al., 2019).

Another study revealed that these parents suffered from high severity of psychological distress due to children's behaviors and problems in doing daily activities. It had been documented those parents of children with autism had a greater lifetime frequency of the major mood disorders (Ahmad Zam Zam et al., 2019). According to a previous study, parents of children with autism spectrum disorder were frequently acknowledged with stress, worry and, depression symptoms. Such distress was prevalent and measured with the Depression Anxiety Stress Scale (DASS) questionnaire among parents of children with autism spectrum disorder who had a comparable demographic background except for academic achievement (Al-Farsi et al., 2016). According to Al-Farsi et al (2016), depression symptoms or a depressed mood had thought to be the most prevalent psychological distress. These findings showed that institutions should pay close attention to parents' mental health requirements, particularly the avoidance of depressive disorders, support and help for parents who were having distress.

### Conclusions

In general, this study discovered that most parents of special needs children were experiencing psychological distress. The most significant fact or which influenced this psychological distress was occupation status since having special needs children increased the financial burden. Thus, the study concluded other factors other than the job status were not affecting the severity of the parent's psychological distress.

### Acknowledgments

The authors would like to express gratitude to all the respondents for participating in this study.

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