

Parental Stress in Caring for Children with Disability

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Abstract

Caring for children with disability can be tremendously challenging and exhausting, causing stress to parents and affecting the family's well-being. This study aimed to identify the level of stress and contributing factors to stress among parents of children with disability. The questionnaire was administered to 150 respondents who have children with disability in Johor Bahru district. Data were analyzed using descriptive analysis involving percentages, mean scores, and standard deviations. The study showed moderate parental stress ($M=2.58$, $SD=1.20$). The contributing factors to stress are family socioeconomics ($M=3.33$, $SD=1.33$), fatigue managing children's daily routine ($M=3.25$, $SD=1.15$), and children's health problems ($M=3.13$, $SD=1.40$). Growing up with a disabled child is no easy task, unless parents have more patience. Government and non-governmental organisations (NGO) could organize more programmes and events to strengthen parenting skills. Psychological, social, and emotional supports help parents to recognize, understand and manage their stress effectively.

Keywords: Parental Stress, Care, Children with Disability, Contributing Factors, Coping Strategies

Introduction

A study by Valicenti-McDermott et al (2015) reported that parents who care for children with a disability experienced more stress than parents with typical children. Children with disabilities require more attention from parents, including modifying tasks to accommodate their children's needs (van Tongerloo et al., 2014). The burden of caring for children with disabilities does not decrease with age. Parents of children with disabilities face complex challenges and have high parenting demands, such as health issues, speech impairment, motor skill deficits, and behavioral problems. The cost of raising children with disability is three times higher than typical children, especially for treatment services, early intervention programs, or therapy (Hu et al., 2015). As a result of constant supervision, parents become exhausted and stressed.

For low-income families, caring for children with disability is a herculean task in which parents require tremendous effort to look after their children (Ilias et al., 2018). Parents feel

stressed to bear the heavier caregiving demands, especially for families with children with physical disabilities that need a wheelchair to live in their daily lives, such as moving, bathing, and going to the toilet. The constant dependent on care results in parents spending a lot of time and energy managing their children's daily routines. Therefore, parents need to know and understand the causes of stress and use appropriate coping strategies to deal with stress. With this, parents are better prepared, have good self-control and emotions, and face stress more positively.

Children with a disability who have health problems need meticulous care, causing stress on parents (Holly et al., 2019). Stress experienced by parents includes the acquisition of information about the disability and managing therapy services and treatment. Parents face difficulties obtaining sources of information about treatment and therapy, leading to anxiety and depression (Taderera & Hall, 2017). For example, parents need to help their children get suitable therapy or treatment services to prevent the child's condition from deteriorating and mitigate their illness. Lack of knowledge about children's disabilities causes parents to feel confused, and unprepared to face difficulties caring for their children.

Limitations to access health services in urban areas is a constraint for children with disability to get the necessary service support. Parents often have to reduce their working hours or quit jobs to provide comprehensive support for their children due to widespread barriers to accessing health care including medical treatment and therapy (De Paula et al., 2020). The lack of health care in rural areas causes parents to feel helpless, overwhelmed, and discouraged (Mikolajczak et al., 2019). This problem becomes an obstacle for parents to meet the needs of their children.

In such circumstances, families with disabled children often have difficulty coping with stress. Their emotional coping strategies tend to adversely affect their judgment and lead them to act rashly and with poor judgment. The parental stress of caring for children with disability is a significant concern to all parties because it affects the family's functioning and development (Cantwell et al., 2015; Choi & Yoo, 2015). Consequently, this issue exacerbated parental stress and negatively impacted the well-being of the family (Chan et al., 2018). Hence, parents must strengthen their parenting skills so that they will be able to understand coping strategies and recognize how to control their emotions.

The study's objectives are

- To identify the level of stress among parents of children with disability
- To identify the contributing factors to stress among parents of children with disability

Literature Review

The demands of parenting in caring for children with disability are complicated and influenced by various factors. This section explains the stress of caring for children with disability and factors that contribute to parental stress.

Stress in Caring for Children with Disability

Parents who care for children with disability experience elevated stress compared to typical children (Cuzzocrea et al., 2016; Schnabel et al., 2020; Gordon & Hinshaw, 2017; Hutchison et al., 2016; Phillips et al., 2017). A child with a disability often affects the whole family unit and multiple aspects of parents' lives. Roskam et al (2017) explained that parents quickly feel tired and exhausted taking on the responsibility of being a parent. The fatigue of handling household chaos affected parents more likely to be less responsive toward their children and

have the impression that caring for children with disability is very burdensome (Trentacosta et al., 2018). Therefore, parents rarely interact with their children, causing them to be marginalized and neglected (Schiltz et al., 2018).

Mcbean & Schlosnagle (2015) reported that parents who care for children with disability experience sleep disturbances and have poor sleep quality compared to parents with typical children. The high commitment of caring for children with disability causes stress and anxiety among parents (Bujnowska et al., 2019). Parents who have children with disability experience poor mental health and low quality of life (Alnazly & Abojedi, 2019; Alshekaili et al., 2019; Huang et al., 2019). Parents need to balance their roles in self-management, basic life skills, behaviour management, therapy services, and career transition planning to help their children to live independently.

Contributing Factors to Stress in Parents of Children with Disability

Various factors contribute to stress in parents who have children with disability. Among them are the family's socioeconomic status, children's behaviour problems, and health problems of children with disability. The family's low socioeconomic status is reported as a contributing factor to stress among parents who care for children with disability (Kamaruddin & Mamat, 2015). This is due to parents have to balance work, life, and work demands. The situation becomes complicated when their children require unique and special health care. 11.2 million children with a disability under 18 in the United States require intensive medical and therapy services (U.S. Department of Health and Human Services, 2013). The high cost of medical needs increases the financial burden, especially for families with many siblings.

Parents who care for children with disability are reported to have higher stress related to their child's behaviour problems (Argumedes et al., 2018; Barroso et al., 2018). Hebron et al (2015) explained that children with disability face difficulties in controlling behaviour and often display problematic behaviour. The situation becomes critical when children suffer from emotional disturbances and tantrums, often doing inappropriate behaviour such as damaging things, biting others, and hurting themselves. This situation causes parents to lose motivation to control their children's behaviour (Stone et al., 2016). Antonopoulou et al (2020) opinions that behavioural problems and emotional disturbances in children with disability can contribute to parental burnout. Parental depression has been shown to increase as a result of the problematic behaviour of children with disability (Giovagnoli et al., 2015; Yorke et al., 2018).

Menon et al (2020) explained that the stress of parents who have children with disability is related to the child's health problems. Most parents place high expectations on their children. However, their children tend to have disabilities, including social and communication and physical problems, requiring intensive treatment. In this case, parents must seek ongoing treatment or therapy services for their children. The lack of psychiatrists and therapists results in children with disability having to take a long time to get medical treatment (Paula et al., 2020). This situation creates anxiety for parents and causes them to feel depressed.

Parental stress of children with a disability needs to be taken seriously and paid attention to by all parties. Several interventions are used to deal with the stress of parents with children with disability (Da Paz & Wallander, 2017). For example, social support in encouragement, motivation, and encouragement can reduce parental stress (Cetinbakis et al., 2020). Sharing information and guidance from solid professional experts is needed to help children with disability achieve better development (Gustafsson & Granlund, 2015). With this, support and guidance can help parents of children with a disability deal with problems more

effectively and become strong supporters of their children. Therefore, this study aims to identify the level of stress and factors associated with parental stress of children with disability.

Methodology

This study is conducted in the form of a survey to make it easier for researchers to decide what to study, the questions asked, and the scope of the questions. The respondents were selected through a simple random sampling technique involving 150 parents with children with special educational needs in the Johor Bahru district. The questionnaire was adapted from the Parenting Stress Index Fourth Edition (PSI-4) and was administered using the google form. The respondents were to choose the appropriate response based on a five-point Likert scale. Data collected were analyzed through descriptive statistics involving percentage values, frequency, and mean scores.

Findings

The findings of the study are divided into two parts. The first part is related to the stress level, while the second part is the factors contributing to parental stress of children with disability.

Level of Parental Stress in Caring for Children with Disability

Table 1 discusses parental stress in caring for children with disability. As a result of the findings on the items in this construct, it was found that all the items measured were at a moderate level except for the fourth and seventh items. A mean score of 3.96 (SD=1.18) was recorded in item seven, with 72.6% of respondents agreeing that their children need more attentive care than typical children. Item four recorded the lowest mean score (M= 1.55, SD = 0.93), where 67.3% of respondents did not regret giving birth to their children. Parents had a moderate stress level, with an overall mean score of 2.58 and a standard deviation of 1.20. This proves that most respondents are somewhat satisfied with the care of children with disability.

Table 1

Distribution of frequency, mean, and level of parental stress in caring for children with disability

No	Item	Frequency (Percentage)					Mean	Standard deviation	Interpretation of min
		SD	D	N	A	SA			
1.	When I do something for my child, I feel that my efforts are not appreciated.	44 29.3%	40 26.7%	42 28%	17 11.3%	7 4.7%	2.35	1.15	moderate
2.	I am easily disappointed if my child is not able to meet my	25 16.7%	38 25.3%	43 28.7%	32 21.3%	12 8%	2.78	1.19	moderate

	expectations								
3.	I often feel tired, have back pain and have trouble sleeping.	34 22.7%	33 22%	33 22%	39 26%	11 7.3%	2.73	1.27	moderate
4.	I regret about having my child.	101 67.3%	24 16%	19 12.7%	3 2%	3 2%	1.55	0.93	low
5.	I am disappointed in myself for not being able to educate my child well	36 24%	32 21.3%	37 24.7%	30 20%	15 10%	2.71	1.30	moderate
6.	I no longer care about other people like I did before.	50 33.3%	38 25.3%	30 20%	21 14%	11 7.3%	2.36	1.27	moderate
7.	My child needs more careful care than a typical child.	9 6%	10 6.7%	22 14.7%	45 30%	64 42.6%	3.96	1.18	high
8.	I feel like every time my son does something wrong, it's actually my fault.	36 24%	34 22.6%	46 30.7%	27 18%	7 4.7%	2.56	1.17	moderate
9.	I feel lonely and have no friends to share my problems with.	51 34%	36 24%	28 18.7%	20 13.3%	15 10%	2.43	1.34	moderate
10.	I am no longer interested in doing something I like or am passionate about.	45 30%	45 30%	34 22.7%	16 10.7%	10 6.7%	2.34	1.20	moderate
Overall mean							2.58	1.20	moderate

(Key: SD= Strongly disagree, D= Disagree, N= Neutral, A=Agree and SA= Strongly agree)

Contributing Factors to Parental Stress in Caring for Children with Disability

Table 2 elaborates on the factors contributing to the parental stress of children with disability. The second item, the family's socioeconomic factor, recorded the highest mean score (M=3.33, SD=1.33). The second highest score is on the ninth item, which is the fatigue factor of managing the child's daily routine (M=3.25, SD =1.15). The item with the lowest mean score is the eighth item, the respondents feel powerless to communicate with their children (M=2.35, SD =1.07). The average mean of the whole item is at a medium level, with a mean score of 2.81 and a standard deviation of 1.23

Table 2

Distribution of frequency, mean, and contributing factors to parental stress of children with disability

No.	Item	Frequency (Percentage)					Mean	Standard deviation	Interpretation of min
		SD	D	N	A	SA			
1.	I feel tired of managing my child's problematic behavior.	32 21.3%	35 23.3%	44 29.3%	28 18.7%	11 7.3%	2.67	1.21	moderate
2.	I often face financial problems to get appropriate treatment due to the high cost of treatment.	19 12.7%	21 14%	39 26%	34 22.6%	37 24.7%	3.33	1.33	moderate
3.	I had to work part-time to supplement the family income.	32 21.3%	20 13.3%	42 28%	31 20.7%	25 16.7%	2.98	1.36	moderate
4.	I had to take my child to seek medical treatment far from my home.	24 16%	34 22.7%	46 30.7%	25 16.7%	21 14%	2.90	1.26	moderate
5.	I often take time off or quit work to take care of a child who has health problems.	27 18%	23 15.3%	38 25.3%	27 18%	35 23.3%	3.13	1.40	moderate
6.	I felt embarrassed and stressed to explain my	42 28%	46 30.7%	37 24.6%	12 8%	13 8.7%	2.39	1.22	moderate

	son's condition to the local community.									
7.	I feel disappointed when the teacher mentions my child's problems at school.	30 20%	37 24.6%	45 30%	28 18.7%	10 6.7%	2.67	1.18	moderate	
8.	I feel powerless to communicate with my child.	36 24%	52 34.7%	40 26.7%	17 11.3%	5 3.3%	2.35	1.07	moderate	
9.	I am busy to manage my child's daily life.	10 6.7%	33 22%	38 25.3%	47 31.3%	22 14.7%	3.25	1.15	moderate	
10.	I feel angry about my child's behavior problems when he is inside or outside the house.	36 24%	43 28.7%	46 30.7%	19 12.6%	6 4%	2.44	1.10	moderate	
Overall mean							2.81	1.23	moderate	

(Key: SD= Strongly disagree, D= Disagree, N= Neutral, A=Agree and SA= Strongly agree)

Discussion

This section discusses the level of stress and factors that contribute to stress for parents who have children with disability. Most respondents revealed that their children require more attentive care than typical children. Meanwhile, parenting stress is influenced by various variables. For that, parents who have children with disability need to identify contributing factors that lead to stress.

Level of Parental Stress in Caring for Children with Disability

The results indicate that parental pressure is moderate, and most parents can still control themselves when feeling stressed. A study by Bhatia et al (2015) insisted that parents who take care of children with disability have a moderate level of stress. Meanwhile, 82.7 per cent of the study respondents were mothers. This can be linked to the division of duties between mothers and fathers in child care. Vasilopoulou & Nisbet (2016) believe that the father's involvement in household chaos is less due to traditional factors that consider it a duty for the wife. A study by Pepperell et al (2018) attested that mothers dominate in managing household chaos. The imbalance of women's roles between career and home encourages

them to avoid engaging in careers and becoming full-time homemakers. The involvement of fathers is less encouraging, likely due to the different study sampling methods used in this study.

Despite facing challenges in caring for children with disability, most respondents revealed that they did not regret having children. 60% of respondents disagreed that they lost interest in doing something they liked. This finding is consistent with the findings of Hoefman et al (2013) that parents with children with disability derive satisfaction from caring for their children. However, 72.6% of the respondents said their children need more attentive care than typical children. A study by Schiltz et al (2018); Chan & Lam (2017) prove that parents who have children with disability are at risk of experiencing stress and depression. The study of Bujnowska et al (2019); Scherer et al (2019) also asserted that parents who take care of children with disability experience stress. This is related to the heavier burden of duties and care, especially for working parents who have to balance work and family time.

Children with a disability usually require a high commitment from both parents (Obeid et al., 2015). Cronin et al (2015) explained that the stress experienced by parents causes them to feel that they cannot take on the responsibilities as parents. Their children need unique guidance and nurturing compared to typical children. In educating and raising children with disability, parents need to balance their roles because their tasks focus on the basic needs of life and involve the child's learning process, behavioural and emotional management, basic life skills, therapy, and medical services. Many parental workloads have psychological effects and affect parents' mental health (Luo et al., 2021).

Contributing Factors to Parental Stress in Caring for Children with Disability

A study by Pinquart (2017); Bornstein (2019) agreed that parents who care for children with disability experience high parental stress. In this study, financial problems are the main cause of stress for parents who have children with disability. Most respondents work part-time to cover basic living needs and expenses related to medical services. Hu et al (2015) agreed that financial resources are the main component for families with children with disability. Sturge-Apple et al (2014); Leininger & Kalil (2014) agreed that caring for children with disability is challenging and requires high expenditure. Without substantial financial resources, the need to obtain quality treatment services for children with disability will be compromised.

Disability factors and children's health problems are said to be stress triggers for parents who care for children with disability. Overseas researchers say that the stress of parents who care for children with various combinations of disabilities is higher than children with learning disabilities (Craig et al., 2016). This study is in line with the opinion of Almogbel et al (2017) that the stress of parents who have children with multiple disabilities is 5.5 times higher than parents who have children with intellectual disabilities. Holly et al (2019); Gagnon et al (2020) think that the health problems of children with disability increase parents' anxiety. It is proven that health problems and disabilities cause stress in parents of children with disability.

The tiredness of managing children's daily routines leads to parental stress. The study's findings show that most parents are busy managing their children's daily lives regarding self-management, academics, essential learning, motor, social and communication skills, and emotional and behavioural problems. Some parents revealed they had problems with insomnia, extreme fatigue, and back pain (Mcbean & Schlosnagle, 2016). Low sleep quality disrupts psychology and mental well-being (Lo Martire et al., 2020). As a result, parents face the risk of stress and other negative impacts on children's development.

The study's findings revealed that parents are less stressed and do not feel ashamed to explain their children's condition to the local community. This is likely because the awareness and understanding of people with special needs are increasing in Malaysia. However, Kinnear et al (2016); Scior et al (2016) also opined that parents who take care of children with disability are often faced with negative perceptions from society.

Behavioural problems of children with disability are said to be related to parental pressure. However, most parents disagree that they are tired of managing their child's problematic behaviour. This is likely due to involvement in an appropriate therapy program helping them to control their child's behaviour. The findings of this study contradict the opinion of Argumedes et al (2018); Barroso et al (2018) that behavioural problems contribute to parental stress, especially for children with behavioural problems.

Conclusion

Overall, the majority of parents with children's disabilities are still able to control themselves when feeling stressed. This confirms that parents have a moderate level of satisfaction and can respond to the pressures they face. However, raising children with disability is very challenging and requires full attention from parents. In this regard, parents who experience varying parenting demands are easily discouraged and tend to experience high anxiety. Concerning that, parents need to be given parenting knowledge and get social support to reduce stress and deal with issues related to child care.

Most studies on parenting stress have focused more on macro factors such as family background and societal stigma. Parental stress on children with disability in Malaysia is less studied from the perspective of parental personality. Therefore, further research is recommended to focus on the attitude and readiness of parents to manage stress. The ability of parents to recognize and manage their own emotions positively impacts children's development.

This study is intended to provide the community with a better understanding of why children with disability behave in such a problematic manner. Parents who care for children with disabilities can benefit from valuable information regarding parenting stress obtained from this study. In addition, it can uncover effective solutions to alleviate stress. This study may also provide guidance and inspiration for researchers in the future who are considering research in this field.

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