

Article

Psychological Well-Being of Parents with Down Syndrome Children: The Role of Demographics

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Abstract: This study investigated the under-researched area of psychological well-being among parents of children with Down syndrome, addressing a gap in existing literature that primarily focuses on factors like stigma and social support in isolation. Guided by self-stigma theory and social support theory, this research aimed to provide an integrated examination of the interplay between parental demographics, perceived stigma, social support, and psychological well-being. A cross-sectional quantitative approach was employed, surveying 351 parents from 11 inclusive schools and one special needs school. Questionnaires were used to assess demographics, stigma (Parent Self-Stigma Scale), social support (Multidimensional Scale of Perceived Social Support), and psychological well-being (Six-Factor Model of Psychological Well-being). Data analysis included descriptive statistics, Pearson's correlation, linear regression, and Bayesian analysis. The study's key findings indicated that parental demographics, particularly education and employment levels, significantly predicted psychological well-being. Higher education levels were found to correlate with increased resource access and better understanding of the child's condition. Whilst stigma and a paucity of social support do not directly impact income or well-being, age and family size have mediating effects, with parental and child age also playing significant mediating roles. Notably, social support mediates the relationship between the child's psychological well-being and overall parental well-being. The study emphasises the necessity of incorporating demographic context, age-related challenges, and the pivotal role of social support networks in promoting favourable outcomes for families raising children with Down syndrome. Future interventions should prioritise empowering parents through educational initiatives, resource provision, and the cultivation of robust support system.

Keywords: Down Syndrome; demographic; parental psychological well-being; social stigma; social support

Introduction

Down syndrome is a genetic disorder that is characterised by a number of physical features, including a smaller head size, a flat back of the head, small or abnormally shaped ears, outwardly turned up eyes, and a folded tongue (Bull, 202). In addition to these physical features, people with Down syndrome also have a higher risk of health problems, including congenital heart disease. A recent study by Putri and Maritska (2022) sought to identify methods that could mitigate the impact of trisomy 21 on the physical and cognitive development of Down syndrome. Annually, 6,000 newborns are diagnosed with Down syndrome, representing one Down syndrome case for every 700 newborns (Mai et al., 2019). The statistical data centre of the Centers for Disease Control (CDC) has explained that, in recent years, children with Down syndrome have a reduced life

expectancy due to the need for special care and support to meet their needs throughout their lives (Shin et al 2019, Espinosa 2020). Their health conditions may require long-term care, medications, and specific therapies, and it is important to ensure that they have access to adequate health services.

The prevailing assumption is that stigma exerts a detrimental influence on the psychological well-being of parents of children with Down syndrome (Edwards 2019). Stigma is defined as a negative view of an individual or group, characterised by the presence of distinguishing characteristics or traits that are considered abnormal by the prevailing societal norms. In the context of Down syndrome, the stigma can be understood as the prevailing negative attitude and beliefs towards children with Down syndrome, who, by virtue of their unique mental and physical health profile, are perceived to be different from the general community. This stigma has been found to have a detrimental effect on the psychological well-being of parents raising children with Down syndrome (Jacob & Sikora 2015). The level of psychological well-being of parents with children who have Down syndrome has been found to be closely related to the negative stigma they face, to the extent that it can even affect their professional activities (Riaz et al. 2022).

The psychological well-being of parents with children with Down syndrome has been found to be positively influenced by social support. Social support can be defined as the perception and reality that an individual is cared for and receives support from the community, friends, and neighbours (Rodriguez et al. 2018). Emotional support is a form of social support, and can take the form of care and assistance. The psychological well-being of parents of children with Down syndrome has been found to be enhanced by social support (Nelson et al., 2016). For instance, emotional social support can be provided by community groups, such as those formed by parents of children with Down syndrome (Buyukavci et al., 2019). These groups offer support to parents and children with Down syndrome, enabling them to participate in activities with their peers at school. The efficacy of such social support in enhancing parental psychological well-being has been well-documented (Nelson et al., 2016; Wahdah, 2022).

A previous study by Widhaya et al (2020) posits that low-income parents may encounter challenges in meeting the health and special needs of children with Down Syndrome. A separate study by Handayani and Pratami (2020) explores the relationship between social support and the psychological well-being of parents who have children with Down Syndrome. Isfani and Paramita's (2021) study posits that parental demographics can influence the nature and extent of social support received. Darla and Bhat's (2021) study on stigma contends that it has a detrimental impact on the psychological well-being of parents with children who have Down syndrome. The study by Badriatuzzaroh, Supraptiningsih, and Hamdan (2018) posits that the social media presence of children with severe Down syndrome can influence the stigma surrounding the condition, thereby impacting the psychological well-being of parents. The study by Hamlett et al (2018) underscores the role of gender in shaping perceptions of stigma and self-acceptance. The impact of social and cultural variations in expectations and demands placed on parents is a subject of exploration in the research conducted by Saputra et al (2018), Priwanti et al (2018) and Patilima et al (2021).

The role of social support in influencing the psychological well-being of parents of children with Down syndrome is a pivotal area of investigation. A separate study by Ali et al (2020) examined the effect of social support on the psychological well-being of parents of children with Down syndrome. However, the study only focuses on looking at the influence between stigma and social support affecting psychological well-being linearly. A further study by Hölling (2021) explored the age factor of parents as a mediator between the influence of stigma and social support on the psychological well-being of parents who have children with special needs. However, this study did not consider demographic factors of parents, such as education and income. This is consistent with the findings of Kwong et al. (2021), who examined mediators to ascertain how the age and income level of parents influence the relationship between stigma, social support, and the psychological well-being of parents of children with Down syndrome.

The central question guiding this study is to what extent the stigma faced by parents affects their psychological well-being, and whether social support can influence their psychological well-being, counteracting the potentially negative impact of stigma. The study also explores how demographic factors such as parents' occupation, income level, and age influence the relationship between stigma and social support on psychological well-being. The study's findings offer significant insights and information, particularly in

relation to the psychological and social aspects of caring for children with Down syndrome. The results of this investigation can contribute to the development of tailored interventions and programs for parents of children with Down syndrome in Riau, with the aim of enhancing their psychological well-being, especially in terms of psychological health and social support.

Literature Review

Goffman (1963) defines stigma as negative stereotypes and social discrimination associated with certain individuals or groups, which can result in exclusion and a decline in mental and emotional well-being. Neel and Lassetter (2019) expand on this definition, emphasizing that stigma is a negative perception or stereotype attached to a person or group, which gives the impression of discrimination and social rejection. Newton and McCabe (2005) add that stigma includes negative beliefs that one person holds towards other individuals, which underlie the perceived injustice of a group. Recent research also shows that stigma, especially that related to conditions such as Down syndrome, can significantly reduce the psychological well-being of parents

Gao and McLellan (2018) define psychological well-being as a state that includes happiness, life satisfaction, and sustainability experienced by individuals or society as a whole, from physical, mental, and socioeconomic perspectives. Ryff and Keyes (1995) also emphasize that psychological well-being is a state in which individuals or societies feel happy and fulfilled in various aspects of life. Butler (2016) explains that social support is an individual's effort to obtain and receive emotional support, as well as social resources that function as a counterbalance to stress, thus improving mental well-being. Support can come from a variety of sources, including family, friends, and community. Cohen and Wills (1985), as cited by Morgan et al. (1991), define social support as a series of relationships that generate a sense of connectedness, compassion, and appreciation in individuals. Recent research reinforces that social support has an important role in improving psychological well-being, especially in parents who face challenges in caring for children with special needs

Hales et al. (2018) define demographics as the characteristics of the human population in terms of numbers, growth, age structure, geographical distribution, and other factors such as education, occupation, and gender. Li et al. (2020) add that demography is the study of population distribution and change, including trends in growth, birth, death, and migration. Lauer and Houtenville (2018) define demography as the collection, analysis, and interpretation of statistical data about the human population. Recent research shows that demographic factors such as age, income, and occupation can moderate the relationship between stigma, social support, and psychological well-being. For example, older people with higher incomes may have access to better resources to cope with the stress associated with stigma

Methodology

This study had used a quantitative approach with a cross-sectional design to investigate and analyze the relationship between stigma, social support, psychological well-being, and demographic characteristics in parents of children with Down syndrome. The study was conducted in Riau Province from late July to late September, focusing on schools with the highest number of children with Down syndrome. Eleven schools, including SLB Sri Mujinab and other inclusive schools, had been selected as data collection locations. A total of 351 respondents, who were members of the POTADS and IDSI groups in Riau, participated in this study by completing a self-administered questionnaire. The sample size had been calculated using the Raosoft sample calculator, with a margin of error of 5% and a confidence level of 95%.

The selection of Riau Province as the research location was based on several considerations. First, Riau had a significant population of children with Down syndrome, identified through the active POTADS and IDSI communities. Second, accessibility and good cooperation with inclusive schools and special schools in Riau had made the data collection process easier. Third, the socio-cultural characteristics in Riau, which might have differed from other provinces, provided a unique context for understanding the influence of stigma and social support. This research protocol had received ethical approval from the Faculty of Medicine, Universiti Kebangsaan Malaysia (UKM) with reference number UKM/PPI/111/8, and also from the Faculty of Medicine, National University of Malaysia with reference number JEP-2024-1-1104. The ethics approval process had included a review of the research protocol, research instruments, and data collection procedures to ensure the

protection of participants' rights and welfare. Participants were provided with complete information regarding the purpose of the study, data collection procedures, and their right to withdraw at any time.

The inclusion criteria for participants in this study were: (1) having a child with Down syndrome who was registered in the POTADS or IDSI community; (2) being able to read and understand the questionnaire; and (3) being willing to participate in the study. The exclusion criteria were: (1) not having a child with Down syndrome or not being registered in the community; (2) unable to read or refusing to participate; and (3) family members other than biological parents, even if registered in the community. The data collection technique involved distributing questionnaires to parents. The questionnaire consisted of five main sections: (1) respondent demographics, (2) stigma, (3) social support, and (4) psychological well-being. Stigma was measured using the Parent Self-Stigma Scale (PSSS), social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS), and psychological well-being was measured using the Six-Factor Model of Psychological Well-being. The data were analyzed using various statistical methods, including descriptive statistics with SPSS for Windows, Pearson correlation, linear regression analysis, and Bayes analysis. These methods were used to evaluate bivariate correlations between variables, direct influences, and to test the mediating or moderating role of variables in influencing psychological well-being.

The Findings

1. Parent's Demographics

The data was gathered by surveying 351 parents of children with Down syndrome in Riau. (Table 1) shows the demographic profile of the 351 participants. The gender distribution of the participants was practically even, with 172 men (49.3%) and 179 females (50.7%). In terms of marital status, the majority of respondents were married, with 253 (72.10%), while 98 (27.90%) were divorced. The bulk of the parents were in their late 30s or early 60s, accounting for 277 people (78.5%). This was followed by parents in their early twenties (18-29 years), who accounted for 72 persons (20.5%), while just two people (6%) were elderly (above 60 years old). In terms of educational achievement, the majority of participants had at least a bachelor's degree, with 297 (84.60%) completing a bachelor's program and 12 (3.40%) earning a master's degree. Furthermore, 21 persons (6.0%) had only completed 12 years of school, 8 (2.30%) had occupational credentials, and 9 (2.60%) had a diploma. In terms of occupation, the majority of respondents (216, 61.50%) were freelancers, followed by 32 (9.10%) public workers, 15 (4.30%) teachers, and a lesser number of physicians, attorneys, and entrepreneurs. In terms of age, the largest group was that of children aged 7-11 years, which included 197 persons (56.10%), followed by pre-school children (3-6 years), with 69 people (19.70%), and teens (12-17 years), with 82 people (23.40%). The total number of children per household showed that the majority of participants (41.90%) had two children, followed by families with one kid (31.60%), three children (22.50%), and 4.0% had four or more children. The table gives a detailed summary of the respondents' demographic data, including gender, marital status, parents' age and education, employment, and information about their children.

Table 1. Parent's demographic

Demographic Profile		Total	(%)	Demographic Profile		Total	(%)
Gender	Male	172	49.3	Marital Status	Married	253	72.10
	Female	179	50.7		Divorced	98	27.90
Parent's Age	Early Adulthood (18-29)	72	20.5	Income	Low	116	33.0
	Late Adult (30-60)	277	78.5		Middle	205	58.40
	Elderly (60 >)	2	6		High	27	7.70
Education	12 Years School	21	6.0	Job/Profession	freelance	216	61.50
	Vocational	8	2.30		Freelance with contract	15	4.30
	Diploma III	9	2.60		Housewife	22	6.30

Demographic Profile		Total	(%)	Demographic Profile		Total	(%)
Child's Age	Bachelors	297	84.60	Pilot	1	0.30	
	Masters	12	3.40	Entrepreneur	6	1.70	
	Police Academy	1	0.30	Veterinarian	1	0.30	
	Army Academy	3	0.90	Photographer	2	0.60	
	Preschoolers (3-6 y.o)	69	19.70	Driver	5	1.40	
	Children (7-11 y.o)	197	56.10	Lawyer	2	0.60	
	Early Childhood (12-17 y.o)	82	23.40	Sivic Servant	32	9.10	
	Middle child (18-21 y.o)	3	0.9	Teacher	15	4.30	
				Lecturer	2	6.0	
				Doctor	6	1.70	
Total of Child	1 child	111	31.60	Retirement	2	0.60	
	2 children	98	41.90	Priest	2	0.60	
	3 children	79	22.50	Police	2	0.60	
	4 children (and more)	14	4.0	Army	3	0.90	
	Total	351	100%	Total	351	100%	

Source: Data Demographic (2024)

2. Mediating Factors of Demographic Toward Psychological Well-Being of Parents With Down Syndrome

As demonstrated in Table 2, the analysis demonstrates that there is no statistically significant relationship between stigma and income level (p -value -0.0052 , $p = 0.1877$) or between stigma and psychological well-being (coefficient -0.0580 , $p = 0.5068$). Furthermore, the parents' income level did not demonstrate a significant effect on psychological well-being (coefficient -1.0703 , $p = 0.3693$). The R^2 value in this model indicates that the analysed variables only explain 7.08% of the variability in parental income and 5.82% of the variability in psychological well-being, suggesting that there may be other factors influencing these two variables. The model's efficacy is evident from the low F value, namely $F(1.7423) = 0.1877$ for the effect between stigma and income level, and $F(0.5855) = 0.5574$ for the effect between stigma and psychological well-being. It is evident that both of these p -values are less than 0.001, thereby indicating an absence of a sufficiently robust relationship between these variables to elicit a statistically significant effect.

The coefficient for social support is -0.0001 , with a p -value of 0.9626, indicating that social support has no significant effect on the parents' income level. Conversely, the level of parental income exhibited a coefficient of -1.0199 with a p -value of 0.0633, suggesting a tendency for the level of parental income to be associated with psychological well-being, though not reaching a significant level. The R^2 for this model is 0.0025, indicating that only 0.25% of the variation in parents' income level can be attributed to social support. In the context of psychological well-being, the coefficient for social support is not significant ($\beta = -0.1225$), and the marginal income level ($\beta = -1.0199$) indicates a possible relationship, albeit not a strong one, which may be influenced by other factors. The R^2 value for psychological well-being is 0.1097, indicating that approximately 10.97% of the variation in psychological well-being can be attributed to these two factors.

In addition, the coefficient of parental age on psychological well-being shows a value of 1.8005 with SE 1.6743, but the p -value of -0.6871 indicates that the decision is also insignificant. The R^2 value for this model is 0.0214, indicating that only 2.14% of the variation in parental age can be explained by stigma, suggesting a rather weak relationship between the two variables. The psychological well-being analysis yielded a p -value of -0.0591 with an SE of 0.0860 and a p -value of 0.4925, indicating that there is no statistically significant relationship between stigma and psychological well-being. Conversely, the R^2 value of 0.0689 indicates that approximately 6.89% of the variance in psychological well-being can be attributed to the age of the parents. Further analysis yielded an F statistic of 0.1602 for the relationship between stigma and parental age, and 0.8305 for the relationship between parental age and psychological well-being. A p -value was calculated, indicating that neither model was statistically significant.

Table 2. Parents' income level as a mediator to the above stigma and social support relationships to parents' psychological well-being

	Parent's income				Psychological Well-Being			
		Coef.	SE	P		Coef.	SE	P
Stigma	<i>a</i>	-0.0052	0.0039	0.1877	<i>c'</i>	-0.0580	0.08147	0.5068
Parent's Income	-	-	-	-	<i>b</i>	-1.0703	1.1906	0.3693
Constant	<i>il</i>	1.9214	0.1378	0.0000	<i>i2</i>	53.9931	3.8147	0.0000
		R ² :0.0708				R ² :0.0582		
		F(1.7423)= 0.1877, p < 0.001				F(0.5855)= 0.5574, p < 0.001		
Social Support	<i>a</i>	-0.0001	0.0030	0.9626	<i>c'</i>	-0.1225	0.0658	0.0633
Parent's Income	-	-	-	-	<i>b</i>	-1.0199	1.1825	0.0633
Constant	<i>il</i>	1.7491	0.1083	0.0000	<i>i2</i>	56.1697	3.1547	0.0000
		R ² :0.0025				R ² :0.1097		
		F(0.0022)= 0.9626, p < 0.001				F(2.1030)= 0.1237, p < 0.001		

Source: Data SPSS (2024)

The mediator table 3 displays the studies carried out to identify the mediator function between parental education and psychological well-being, which is helped by three mediator variables: self-acceptance, stigma, and social support. The self-acceptance measure exhibits a statistically significant positive coefficient ($a = 0.0119$, $p = 0.0004$). However, the direct effect of parental education on psychological well-being is not significant ($c' = -0.1519$, $p = 0.0016$). A substantial positive coefficient for parental education was discovered in the context of stigma ($a = 0.0111$, $p = 0.00662$). However, the observed direct impact demonstrated an insignificant relationship ($c' = -0.610$, $p = 0.4815$). A similar outcome was found for social support, which showed a significant positive coefficient ($a = 0.0097$, $p = 0.0359$) but an insignificant direct impact ($c' = -0.1225$, $p = 0.0644$). The R-squared (R^2) values for each model indicated that self-acceptance ($R^2 = 0.1893$), stigma ($R^2 = 0.0982$), and social support ($R^2 = 0.1121$) influenced psychological well-being, albeit to differing extents. These data indicate that parental education has a major impact on psychological well-being through the mediating effect of self-acceptance, but the direct effect is not significant. The results also suggest that other mediator factors have a different impact on psychological well-being. In conclusion, our findings show that parental education has the potential to impact individuals' psychological well-being. Self-acceptance revealed as the most significant mediator in this study.

Table 3. Parents' Education As A Mediator To The Above Stigma And Social Support Relationships To Parents' Psychological Well-Being

	Parent's Education				Psychological Well-Being			
		Coef.	SE	P		Coef.	SE	P
Stigma	<i>a</i>	0.0111	0.0060	0.00662	<i>c'</i>	-0.610	3.7276	0.4815
Parent's Education	-	-	-	-	<i>b</i>	-0.0077	0.7629	0.9920
Constant	<i>il</i>	2.8527	0.2124	0.0000	<i>i2</i>	52.2049	3.7276	0.0000
		R ² :0.0982				R ² :0.0380		
		F(3.3960)= 0.0662, p < 0.001				F(0.2515)= 0.9998, p < 0.001		
Social Support	<i>a</i>	0.0097	0.0046	0.0359	<i>c'</i>	-0.1225	3.2398	0.0644
Parent's Education	-	-	-	-	<i>b</i>	0.0977	0.7608	0.8979
Constant	<i>il</i>	2.8968	0.1671	0.0000	<i>i2</i>	54.0208	3.2398	0.0000
		R ² :0.1121				R ² :0.0991		
		F(4.4380)= 0.0359, p < 0.001				F(1.7248)= 0.1797, p < 0.001		

Source: Data SPSS (2024)

As seen in the mediator table 4, the study yields numerous noteworthy outcomes. These findings demonstrate the association between several variables that serve as mediators in the impact of child psychology on child well-being. The findings show that self-acceptance is not a significant mediator in children's psychological effect on child well-being ($P = 0.4753$), nor is stigma. In contrast, stigma was

discovered to be a significant mediator in the psychological effect of children on child well-being ($P = 0.0640$). The research also found that social support was a significant mediator in children's psychological effect on their well-being ($P = 0.0015$). This research implies that youngsters with a robust social support network are more likely to demonstrate greater levels of well-being.

Table 4. Child's Age As A Mediator To The Above Stigma And Social Support Relationships To Parents' Psychological Well-Being

		Child's Age				Psychological Well-Being		
		Coef.	SE	P		Coef.	SE	P
Stigma	<i>A</i>	0.0017	0.0035	0.4839	<i>c'</i>	-0.1219	0.0656	0.0640
Child's Age	-	-	-	-	<i>b</i>	0.2169	1.0168	0.8312
Constant	<i>il</i>	1.9963	0.1250	0.0000	<i>i2</i>	53.8708	3.1239	0.0000
R ² :0.0259					R ² :0.0995			
F(0.2341)= 0.6288, $p < 0.001$					F(1.7394)= 0.1771, $p < 0.001$			
Social Support	<i>A</i>	-0.0101	0.0030	0.0010	<i>c'</i>	-0.1526	0.0477	0.0015
Child's Age	-	-	-	-	<i>b</i>	-0.5405	0.8299	0.0015
Constant	<i>il</i>	3.0564	0.3246	0.0000	<i>i2</i>	67.3734	0.8299	0.5153
R ² :0.1750					R ² :0.1692			
F(11.0261)= 0.0010, $p < 0.001$					F(5.1253)= 0.0064, $p < 0.001$			

Source: Data SPSS (2024)

Discussion

The results of this study show that the factors of income, employment, education, age, and number of children have a significant influence on the psychological well-being of parents of children with Down syndrome, through the mediation of social support and stigma. Higher incomes allow for better access to health services, therapeutic interventions, and special education for children (Mas et al., 2019). This is in line with the finding that financial difficulties can increase stress and decrease parental well-being. Jobs with flexible schedules also help parents balance professional and family responsibilities, which is supported by the Working Environment study which shows the importance of emotional support and assistance.

Higher levels of education facilitate a deeper understanding of children's conditions and access to relevant information, as more educated parents may have a wider social network and better resources. As children get older, the needs and challenges parents face also evolve. A study by Mori et al. (2019) shows that the progress of a child's development can be a source of motivation for parents, improving their psychological well-being. However, the birth of another child can divide parents' attention, potentially reducing the time allocated to children with Down syndrome. Although stigma does not statistically show a significant direct effect on psychological well-being, the mediating role of stigma remains relevant. This may be due to effective coping mechanisms of parents, where social support acts as a buffer against the negative impact of stigma. However, it should be noted that the measurement of psychological well-being using self-report questionnaires may have a bias, where participants tend to provide socially desirable answers.

The age of the parents also acts as a mediator. Parents with young children with Down syndrome face greater challenges in care and education, as well as uncertainty about the child's future (Song et al., 2018). Meanwhile, parents with teenagers with Down syndrome may face different challenges, such as helping children develop independence and readiness for adulthood, but also feeling socially isolated (Song et al., 2018; Cheung et al., 2019). The hypothesis that older parents have more resources needs to be clarified. Although a broader life experience can provide an advantage in overcoming challenges, this does not automatically mean greater financial or social resources. Higher income does allow access to better services, reduces stress, and improves well-being (Alon, 2019). However, low income can be an additional burden, especially if parents have to bear the cost of large care. This study has limitations, such as the cross-sectional design that does not allow for the determination of causal relationships, and the use of self-report questionnaires that are prone to bias. Future research can use longitudinal design and more objective data collection methods to strengthen these findings.

Conclusion

The results of this study show that demographic factors, including education, occupation, and age of the child, which are part of socioeconomic status, play a significant role as mediators in the relationship between variables. These demographic factors shape the way parents respond to the diagnosis of Down syndrome, their stage of self-acceptance, and the way they interact with the social environment. This study reveals the multifaceted relationship between stigma and social support for the psychological well-being of parents of children with Down syndrome, with demographic factors serving as a link between these variables.

The implications of these findings are of significant relevance to various stakeholders, including health workers, counselors, and grassroots advocates. For practical application, health workers can integrate socioeconomic status assessments into psychological support services for parents of children with Down syndrome, enabling more personalized interventions. Counselors can develop counseling programs tailored to the level of education and occupation of parents, as well as consider the age of the child in support strategies. Grassroots advocates can focus on awareness campaigns targeting specific socioeconomic groups, reducing stigma in culturally and socially relevant ways. In addition, the formation of peer support groups that consider the age of the child and the employment status of the parents can help increase the effectiveness of social support. For future research, it is advisable to conduct longitudinal studies to understand how the relationship between stigma, social support, and psychological well-being develops over time. Qualitative research can also be conducted to explore the subjective experiences of parents in dealing with stigma and seeking social support, providing deeper insights into their adaptation process. Further research can also consider cultural and religious factors that may influence the relationship between stigma, social support, and psychological well-being in the Indonesian context.

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Informed Consent Statement: The Faculty of Medicine at the National University of Malaysia granted ethics permission for the present study, which will be carried out in a group of parents with children diagnosed with Down syndrome. Prior to the experiment, all volunteers were given a full description of the study's purpose, procedures, and potential benefits. All individuals gave informed consent, affirming their voluntary and coerced-free participation in the study.

Conflicts of Interest: This research was done independently and objectively, with the authors explicitly stating that there is no conflict of interest.

References

- Alcaraz, K. I., Wiedt, T. L., Daniels, E. C., Yabroff, K. R., Guerra, C. E., & Wender, R. C. (2020). Understanding and addressing social determinants to advance cancer health equity in the United States: A blueprint for practice, research, and policy. *CA: A Cancer Journal for Clinicians*, 70(1), 31–46. <https://doi.org/10.3322/caac.21586>
- Antonarakis, S. E., Skotko, B. G., Raffi, M. S., Strydom, A., Pape, S. E., Bianchi, D. W., Sherman, S. L., & Reeves, R. H. (2020). Down syndrome. *Nature Reviews Disease Primers*, 6(1), 9. <https://doi.org/10.1038/s41572-019-0143-7>
- Cachia, R. L., Anderson, A., & Moore, D. W. (2016). Mindfulness, stress and well-being in parents of children with autism spectrum disorder: A systematic review. *Journal of Child and Family Studies*, 25(1), 1–14. <https://doi.org/10.1007/s10826-015-0193-8>

- Cantwell, J., Muldoon, O., & Gallagher, S. (2015). The influence of self-esteem and social support on the relationship between stigma and depressive symptomology in parents caring for children with intellectual disabilities. *Journal of Intellectual Disability Research*, 59(10), 948–957. <https://doi.org/10.1111/jir.12205>
- Caton, S., & Chapman, M. (2016). The use of social media and people with intellectual disability: A systematic review and thematic analysis. *Journal of Intellectual and Developmental Disability*, 41(2), 125–139. <https://doi.org/10.3109/13668250.2016.1153052>
- Cook, R. J., & Dickens, B. M. (2014). Reducing stigma in reproductive health. *International Journal of Gynecology & Obstetrics*, 125(1), 89–92. <https://doi.org/10.1016/j.ijgo.2014.01.002>
- Cotter, E. W., Teixeira, C., Bontrager, A., Horton, K., & Soriano, D. (2017). Low-income adults' perceptions of farmers' markets and community-supported agriculture programmes. *Public Health Nutrition*, 20(8), 1452–1460. <https://doi.org/10.1017/S1368980017000088>
- Craig, F., Operto, F. F., De Giacomo, A., Margari, L., Froli, A., Conson, M., Ivagnes, S., Monaco, M., & Margari, F. (2016). Parenting stress among parents of children with Neurodevelopmental Disorders. *Psychiatry Research*, 242, 121–129. <https://doi.org/10.1016/j.psychres.2016.05.016>
- Dali, K. (2018). The right to be included. *Information and Learning Science*, 119(9/10), 486–513. <https://doi.org/10.1108/ILS-04-2018-0032>
- Dekker, R., & Engbersen, G. (2014). How social media transform migrant networks and facilitate migration. *Global Networks*, 14(4), 401–418. <https://doi.org/10.1111/glob.12040>
- Falk, N. H., Norris, K., & Quinn, M. G. (2014). The factors predicting stress, anxiety and depression in the parents of children with autism. *Journal of Autism and Developmental Disorders*, 44(12), 3185–3203. <https://doi.org/10.1007/s10803-014-2189-4>
- Garbe, A., Ogurlu, U., Logan, N., & Cook, P. (2020). Parents' experiences with remote education during COVID-19 school closures. *American Journal of Qualitative Research*, 4(3). <https://doi.org/10.29333/ajqr/8471>
- Greve, W., & Staudinger, U. M. (2015). Resilience in later adulthood and old age: Resources and potentials for successful aging. In *Developmental psychopathology* (pp. 796–840). Wiley. <https://doi.org/10.1002/9780470939406.ch21>
- Gulyamova, S. T., Manap, J., Amin, A. S., & Omar, N. H. (2024). Reasonable accommodation, career development, and psychological well-being: Autoethnography as a method of qualitative research. *e-BANGI Journal*, 21(4).
- Hakim, F. F. (2021). Dampak keberadaan penderita gangguan jiwa terhadap ketahanan wilayah Kabupaten Jombang. *Sospol*, 7(2), 202–211. <https://doi.org/10.22219/sospol.v7i2.7460>
- Halstead, E., Ekas, N., Hastings, R. P., & Griffith, G. M. (2018). Associations between resilience and the well-being of mothers of children with autism spectrum disorder and other developmental disabilities. *Journal of Autism and Developmental Disorders*, 48(4), 1108–1121. <https://doi.org/10.1007/s10803-017-3447-z>
- Hassan, N., Ismail, R., & Nen, S. (2023). Relationship of mindset, religiosity and subjective well-being of low-income youth in Malaysia. *Psychological Studies*, 68(4), 582–591.
- Breiner, H., Ford, M., & Gadsden, V. L. (Eds.). (2016). *Parenting matters*. National Academies Press. <https://doi.org/10.17226/21868>
- Hendrix, J. A., Amon, A., Abbeduto, L., Agiovlasitis, S., Alsaied, T., Anderson, H. A., Bain, L. J., Baumer, N., Bhattacharyya, A., Bogunovic, D., Botteron, K. N., Capone, G., Chandan, P., Chase, I., Chicoine, B., Cieuta-Walti, C., DeRuisseau, L. R., Durand, S., Esbensen, A., ... Yi, J. S. (2021). Opportunities, barriers, and recommendations in Down syndrome research. *Translational Science of Rare Diseases*, 5(3–4), 99–129. <https://doi.org/10.3233/TRD-200090>
- Hill-Briggs, F., Adler, N. E., Berkowitz, S. A., Chin, M. H., Gary-Webb, T. L., Navas-Acien, A., Thornton, P. L., & Haire-Joshu, D. (2021). Social determinants of health and diabetes: A scientific review. *Diabetes Care*, 44(1), 258–279. <https://doi.org/10.2337/dci20-0053>

- Astiti, I G. A. A. S. L. C., & Valentina, T. D. (2024). Kesejahteraan psikologis orang tua dengan anak berkebutuhan khusus: Literature review. *INNOVATIVE: Journal Of Social Science Research*, 4(1), 8214–8228.
- Ihsan Razman, M. O., & Hoesni, S. M. (2023). Socioeconomic factors and its role in emotion regulation in children from a socio-ecological perspective: A systematic literature review. *e-BANGI Journal*, 20(4).
- Ijezie, O. A., Healy, J., Davies, P., Balaguer-Ballester, E., & Heaslip, V. (2024). Correction: Quality of life in adults with Down syndrome: A mixed methods systematic review. *PLOS ONE*, 19(12), e0315110. <https://doi.org/10.1371/journal.pone.0315110>
- Kamil, N., Fitri, Z. Z., Nasution, H., & Putro, K. Z. (2023). Memahami anak berkebutuhan khusus: Down syndrome. *Murhum: Jurnal Pendidikan Anak Usia Dini*, 4(2), 190–198. <https://doi.org/10.37985/murhum.v4i2.179>
- Kamil, N. K. M., Amin, A. S., Akhir, N. M., Badayai, A. R. A., Zambri, I. M., Sutan, R., ... & Abdullah, W. A. W. (2024). Conceptual skills of people with intellectual disabilities for independent living. *Journal of Southwest Jiaotong University*, 59(2).
- Kamil, N. K. M., Amin, A. S., MdAkhir, N., Badayai, A. R. A., Zambri, I. M., Sutan, R., ... & Abdullah, W. A. W. (2023). Covid-19's impact on the physical environments of people with intellectual disabilities: A systematic literature review. *e-BANGI*, 20(2), 175–187.
- Kamil, N., Amin, A., Zambri, I., Akhir, N., Khairuddin, K., Sutan, R., & Abdullah, W. (2021). Independent living for persons with intellectual disabilities. *International Journal for Studies on Children, Women, Elderly and Disabled*, 13.
- Kristiyanti, E. (2019). Model penyelenggaraan pendidikan inklusif bagi penyandang disabilitas intelektual: Studi kasus di DKI Jakarta. *Indonesian Journal of Religion and Society*, 1(1), 67–79. <https://doi.org/10.36256/ijrs.v1i1.26>
- Lai, W. W., Goh, T. J., Oei, T. P. S., & Sung, M. (2015). Coping and well-being in parents of children with autism spectrum disorders (ASD). *Journal of Autism and Developmental Disorders*, 45(8), 2582–2593. <https://doi.org/10.1007/s10803-015-2430-9>
- Lalvani, P. (2015). Disability, stigma and otherness: Perspectives of parents and teachers. *International Journal of Disability, Development and Education*, 62(4), 379–393. <https://doi.org/10.1080/1034912X.2015.1029877>
- Lebert-Charron, A., Dorard, G., Boujut, E., & Wendland, J. (2018). Maternal burnout syndrome: Contextual and psychological associated factors. *Frontiers in Psychology*, 9. <https://doi.org/10.3389/fpsyg.2018.00885>
- Martin, T., Smith, A., Breatnach, C. R., Kent, E., Shanahan, I., Boyle, M., Levy, P. T., Franklin, O., & El-Khuffash, A. (2018). Infants born with Down syndrome: Burden of disease in the early neonatal period. *The Journal of Pediatrics*, 193, 21–26. <https://doi.org/10.1016/j.jpeds.2017.09.046>
- Matthews, E. J., Puplampu, V., & Gelech, J. M. (2021). Tactics and strategies of family adaptation among parents caring for children and youth with developmental disabilities. *Global Qualitative Nursing Research*, 8. <https://doi.org/10.1177/23333936211028184>
- Melati, R., Mulyani, R. R., & Triyono, T. (2023). Peran orang tua single parent terhadap anak Down syndrome di Bypass Kecamatan Lubuk Begalung. *Edu Society: Jurnal Pendidikan, Ilmu Sosial Dan Pengabdian Kepada Masyarakat*, 1(1), 51–59. <https://doi.org/10.56832/edu.v1i1.16>
- Mirowsky, J., & Ross, C. E. (2017). *Education, social status, and health*. Routledge. <https://doi.org/10.4324/9781351328081>
- Nunik, N. M., Sagala, A. C. D., & Karmila, M. (2022). Pengaruh permainan tradisional jamuran terhadap interaksi sosial anak Down syndrome. *Murhum: Jurnal Pendidikan Anak Usia Dini*, 53–66. <https://doi.org/10.37985/murhum.v3i1.72>
- Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society*, 28(7), 1024–1026. <https://doi.org/10.1080/09687599.2013.818773>

- Page, B. F., Hinton, L., Harrop, E., & Vincent, C. (2020). The challenges of caring for children who require complex medical care at home: 'The go between for everyone is the parent and as the parent that's an awful lot of responsibility.' *Health Expectations*, 23(5), 1144–1154. <https://doi.org/10.1111/hex.13092>
- Przybylski, A. K., & Weinstein, N. (2017). A large-scale test of the Goldilocks Hypothesis. *Psychological Science*, 28(2), 204–215. <https://doi.org/10.1177/0956797616678438>
- Putra, B. M., Fikri, F., & Suroyo, S. (2021). Tipe kepribadian Bigfive dengan pengambilan keputusan dalam memilih parfum di Kota Pekanbaru. *Pustaka: Jurnal Ilmu-Ilmu Budaya*, 21(1), 36–43.
- Raymaker, D. M., Teo, A. R., Steckler, N. A., Lentz, B., Scharer, M., Delos Santos, A., Kapp, S. K., Hunter, M., Joyce, A., & Nicolaidis, C. (2020). "Having all of your internal resources exhausted beyond measure and being left with no clean-up crew": Defining autistic burnout. *Autism in Adulthood*, 2(2), 132–143. <https://doi.org/10.1089/aut.2019.0079>
- Reynolds, C. F., Jeste, D. V., Sachdev, P. S., & Blazer, D. G. (2022). Mental health care for older adults: Recent advances and new directions in clinical practice and research. *World Psychiatry*, 21(3), 336–363. <https://doi.org/10.1002/wps.20996>
- Saputra, H., Wakhid, A., & Choiriyah, Z. (2018). Hubungan antara dukungan sosial dengan penerimaan orang tua anak Down Syndrome. *Jurnal Perawat Indonesia*, 2(2), 62. <https://doi.org/10.32584/jpi.v2i2.41>
- Scott, M., Foley, K.-R., Bourke, J., Leonard, H., & Girdler, S. (2014). "I have a good life": The meaning of well-being from the perspective of young adults with Down syndrome. *Disability and Rehabilitation*, 36(15), 1290–1298. <https://doi.org/10.3109/09638288.2013.854843>
- Sierau, S., Schneider, E., Nesterko, Y., & Glaesmer, H. (2019). Alone, but protected? Effects of social support on mental health of unaccompanied refugee minors. *European Child & Adolescent Psychiatry*, 28(6), 769–780. <https://doi.org/10.1007/s00787-018-1246-5>
- Simorangkir, M. R. R., Siregar, E., Manalu, R. U., Pane, M., & Prasetyono, H. (2023). Peran orang tua anak berkebutuhan khusus menghadapi stigma sosial. *Jurnal Pengabdian Kepada Masyarakat Bangun Cipta, Rasa, & Karsa*, 2(4), 137–142. <https://doi.org/10.30998/pkmbatasa.v2i4.2321>
- Sippel, L. M., Pietrzak, R. H., Charney, D. S., Mayes, L. C., & Southwick, S. M. (2015). How does social support enhance resilience in the trauma-exposed individual? *Ecology and Society*, 20(4).
- Spector, M., & Kitsuse, J. I. (2017). *Constructing social problems*. Routledge. <https://doi.org/10.4324/9781315080512>
- Suroyo, S., & Putra, B. M. (2022). The impact of framing effect: How framing effect affects students in choosing University's major. *Jurnal Analisa Sosiologi*, 11(2).
- Suroyo, S., & Putra, B. M. (2023). Analysis of men's rights as equality movement in 21st century. *The Indonesian Journal of International Clinical Legal Education*, 5(2), 195–220. <https://doi.org/10.15294/ijicle.v5i2.69578>
- Taruscio, D., Cicerchia, A., Ferrara, V., Scaletti, C., Seia, C., & Morricone, M. V. (2024). Enhancing life skills, self-esteem, and lifting of stigma: How culture and the arts can contribute to the well-being of people with rare diseases. In *Culture and the arts for health and well-being* (pp. 91–111). Springer. https://doi.org/10.1007/978-3-031-64288-3_5
- Weiss, J. A., Tint, A., Paquette-Smith, M., & Lunskey, Y. (2016). Perceived self-efficacy in parents of adolescents and adults with autism spectrum disorder. *Autism*, 20(4), 425–434. <https://doi.org/10.1177/1362361315586292>
- Wiseman, F. K., Al-Janabi, T., Hardy, J., Karmiloff-Smith, A., Nizetic, D., Tybulewicz, V. L. J., Fisher, E. M. C., & Strydom, A. (2015). A genetic cause of Alzheimer disease: Mechanistic insights from Down syndrome. *Nature Reviews Neuroscience*, 16(9), 564–574. <https://doi.org/10.1038/nrn3983>
- Zhuang, S., Tan, D. W., Reddrop, S., Dean, L., Maybery, M., & Magiati, I. (2023). Psychosocial factors associated with camouflaging in autistic people and its relationship with mental health and well-being: A mixed methods systematic review. *Clinical Psychology Review*, 105, 102335. <https://doi.org/10.1016/j.cpr.2023.102335>