



Sociology & Cultural Research Review (SCRR)
 Available Online: <https://scrrjournal.com>
 Print ISSN: 3007-3103 Online ISSN: 3007-3111
 Platform & Workflow by: [Open Journal Systems](#)



Coping Strategies and Parental Stress among Parents of Children with Down Syndrome: Gender, Employment, and the Potential Role of Art

Dr. Sidra Ali Khan

Lecturer, Department of Human Development and Family Studies

sidra_shaukat06@yahoo.com

Dr. Samina Mukhtiar

Lecturer Art and Design Department, University of Peshawar

ABSTRACT

This study looked at gender and employment-related disparities in ways to cope and stress levels among parents of children with Down syndrome in Khyber Pakhtunkhwa, Pakistan. A cross-sectional sample of 100 parents (50 mothers and 50 dads) filled out the Brief COPE Inventory and the Parental Stress Scale (PSS). Independent-samples t-tests revealed that mothers scored significantly higher than fathers on overall coping strategies ($M = 101.06$, $SD = 16.80$ vs. $M = 90.12$, $SD = 12.27$; $t(98) = -3.68$, $p < .001$, $d = -0.74$), particularly in active coping ($t(98) = -5.37$, $p < .001$), venting ($t(98) = -3.37$, $p = .001$), positive reframing ($t(98) = -4.80$, $p < .001$), and humor ($t(98) = -3.41$, $p = .001$). Comparisons based on employment status showed that non-working parents reported significantly higher stress ($M = 58.7$, $SD = 4.70$) than working parents ($M = 54.00$, $SD = 5.64$; $t = -3.99$, $p < .001$, $d = -0.90$), as well as greater reliance on coping strategies ($M = 103.8$, $SD = 9.77$ vs. $M = 92.54$, $SD = 15.89$; $t = -3.63$, $p < .001$, $d = -0.79$). Non-working parents showed higher scores on dysfunctional techniques such as denial, drug use, and self-blame ($p < .05$). These data demonstrate that gender and work position have a significant impact on caregiving stress and coping in the Pakistani sociocultural setting. The findings highlight the need of gender-sensitive, culturally responsive, and occupation-inclusive psychological treatments for improving family resilience.

Keywords: Coping Strategies, Parental Stress, Parents of Children, Down Syndrome, Gender, Employment, Potential Role of Art.

Introduction

Down syndrome (DS) is among the most prevalent genetic conditions worldwide. ([European Commission Report, 2019](#)). Additionally, there doesn't exist any pertinent records in Pakistan on the prevalence of persons with DS, however considering that just one in 600 children is born with DS globally (de Graaf et al., 20

DS is a condition resulting from the division of cells defect that results in an extra chromosome 21, which is present in every cell in a person's body. As a result of this excess material in the genome, this condition is also known as Trisomy 21. ([Ghosh et al., 2009](#)). DS is frequently associated with abnormalities in cognitive capacity and physical growth, neurodevelopmental and behavioural issues, and mood and anxiety disorders. ([Moyal et al., 2014](#); [Jonsson et al., 2017](#)), developmental difficulties, a higher risk for a range of health problems, including heart disease, digestive or limb problems, thyroid dysfunction, hearing and vision abnormalities, and obstructive sleep apnoea. ([Bull, 2011](#); [Alexander et al., 2016](#)). These factors impede individuals with Down syndrome from self-care and achieving normal, independent functioning in daily activities, necessitating the involvement of a constant carer. ([Henn et al., 2008](#); [Areias et al., 2011](#); [El-Gilany et al., 2017](#)).

On the other hand, caring for a loved one may be a fulfilling experience. The capacity to develop a positive perspective on the situation and the accompanying tasks can lead to a decrease in the feeling of load and consequently an increase in the quality of life, with favorable consequences on well-being. (Bertrand, 2019). A caregiver's positive attitude about his or her life setting is founded on a variety of personal attributes that enable him to accept reality as a challenge. It is commonly understood that persons with Down syndrome require particular, permanent care that lasts their entire lives and grows increasingly challenging as they age (Carvalho et al., 2015; McCarron et al., 2018). As a result, the caregiver must possess or develop a set of characteristics and talents that will help him cope with the high demands of caring for a person with a handicap. Psychological capital may be a significant strength for caretakers of persons with Down syndrome.

Raising a kid with Down syndrome frequently requires negotiating a complicated network of physical, emotional, educational, and social problems. Research repeatedly shows that parents of children with impairments, including Down syndrome, report higher levels of psychological anguish than parents of generally developing children (Cuskelly et al., 2009; Pisula & Porębowicz-Dörsmann, 2017). Stress might be from managing medical visits, lobbying for inclusive education, dealing with behavioral issues, or living with societal stigma. Gender and work position, in particular, have a significant impact on how parents perceive and manage caregiving stress.

According to research, mothers, as primary caregivers, report greater levels of stress while simultaneously adopting more emotion-focused and problem-focused coping techniques (Hastings et al., 2005). Fathers, despite their increased involvement, may use passive or avoidant coping techniques and may underreport discomfort owing to gendered societal expectations (Pelchat et al., 2003). Similarly, employment status affects stress levels, as non-working parents may face social isolation and financial difficulties, whereas working parents must balance professional commitments with caring responsibilities (Risdal & Singer, 2004). This study seeks to investigate how gender and work position influence coping and stress among parents of children with Down syndrome in Pakistan's socio-cultural environment, where familial duties and economic problems complicate caring dynamics.

Objectives:

1. investigating gender disparities in coping techniques among parents of children with Down syndrome.
2. Evaluate the effect of work status on coping techniques.
3. Compare stress levels of working and non-working parents.
4. To explore the potential role of art-based practices in supporting coping strategies and alleviating stress among parents of children with Down syndrome.

Methodology

Design and participants: A cross-sectional, comparative design was used. The sample included 100 parents (50 mothers and 50 dads) of children with Down syndrome who were recruited from treatment facilities and inclusive education programs in metropolitan locations throughout Khyber Pakhtunkhwa, Pakistan. The Brief COPE Inventory (Carver, 1997) is a multidimensional instrument for examining adaptive and maladaptive coping techniques. The Parental Stress Scale (PSS) (Berry & Jones, 1995) is a validated 18-item measure to assess parental stress. To investigate group differences, independent samples t-tests were

performed using SPSS. Effect sizes were interpreted using Cohen's d. Significance was defined at $p < 0.05$.

Results:

Table 1 Means, Standard Deviations and t-values on brief coping and its subscales between mother and father (N=100)

Variables	Father (n = 50)		Mother (n = 50)		t(98)	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Brief Coping	90.12	12.27	101.06	16.80	-3.68	.000	-16.38	-5.04	-0.74

Table 1 indicates the results of t-test for comparing parental based mean differences on brief coping and its subscales. The table shows that mother of Down syndrome children have higher brief coping as compared to father of Down syndrome children. The mean difference 10.94 on brief coping is highly significant between father and mother of Down syndrome children at $p < .001$

Table 2 Means, Standard Deviations and t-values on Self-distraction between mother and father (N=100)

Variables	Father (n = 50)		Mother (n = 50)		t (98)	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Self-distraction	7.02	1.08	7.48	1.33	-1.901	.060	-.940	.020	-0.38

Table 2 shows the results of t-test for comparing parental based mean differences on self-distraction. The results indicate no significance mean difference between the Mother and Fathers of Down syndrome children on self-distraction.

Table 3 Means, Standard Deviations and t-values on Active coping between mother and father of Down syndrome children (N=100)

Variables	Father (n = 50)		Mother (n = 50)		t (98)	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Active coping	5.62	1.90	7.28	1.07	-5.373	.000	-2.273	-1.05	-1.08

Table 3 highlights the results of t-test for comparing parental based mean differences on Active coping. The results are found to be statistically significant at ($p < .001$) between the mother and Fathers of Down syndrome children. The table shows that mother of Down syndrome children has higher active coping as compared to father of Down syndrome children.

Table 4 Means, Standard Deviations and t-values on Denial between mother and father of Down syndrome children (N=100)

Variables	Father (n = 50)		Mother (n = 50)		t(98)	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Denial	7.06	0.98	7.48	1.30	-1.828	.071	-.876	.036	-0.36

Table 4 explains the results of t-test for comparing parental based mean differences on Denial. The results are found to be statistically non-significant at ($p > .05$) between the Mother and Fathers of Down syndrome children. Whereas figure shows that mother of Down syndrome has slightly higher denial mean as compared to father of Down syndrome children.

Table 4 Means, Standard Deviations and t-values on Substance use between mother and father of Down syndrome children (N=100)

Variables	Father (n = 50)		Mother (n = 50)		t(98)	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Substance use	7.10	0.93	7.42	1.37	-1.37	.175	-.785	.145	-0.27

Table 5 shows the results of t-test for comparing parental based mean differences on Substance Use. The result indicates that there is no significance mean difference between father and mother of Down syndrome parents on the subscales Substance use

Table 6 Means, Standard Deviations and t-values on Use of emotional support between mother and father (N=100)

Variables	Father (n = 50)		Mother (n = 50)		t(98)	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Use of emotional support	7.02	1.10	7.44	1.34	-1.71	.090	-.91	.07	-0.34

Table 6 explains the results of t-test for comparing parental based mean differences on use of Emotional supports. The results are found to be statistically non-significant at ($p > .05$) between the mother and Fathers of Down syndrome children.

Table 7 Means, Standard Deviations and t-values on Use of instrumental support between mother and father (N=100)

Variables	Father (n = 50)		Mother (n = 50)		t(98)	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Use of instrumental support	6.08	1.69	6.86	1.69	-2.31	.023	-1.46	-.109	-0.46

Table 7 explains the results of t-test for comparing parental based mean differences on use of instrumental support. The results are found to be statistically significant at ($p < .05$) between the mother and Fathers of Down syndrome children.

Table 8 Means, Standard Deviations and t-values on Behavioral disengagement between mother and father (N=100)

Variables	Father (n = 50)		Mother (n = 50)		t (98)	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
1. Behavioral disengagement	7.04	1.14	7.50	1.23	-1.94	.056	-.932	.012	-0.39

Table 8 explains the results of t-test for comparing parental based mean differences on use of Behavioral disengagement. The results are found to be statistically non-significant at ($p > .05$) between the mother and Fathers of Down syndrome children.

Table 9 Means, Standard Deviations and t-values on Venting between mother and father of Down syndrome children (N=100)

Variables	Father (n = 50)		Mother (n = 50)		t (98)	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Venting	5.22	1.670	6.32	1.596	-3.367	.001	-1.748	-.452	-0.68

Table 9 explains the results of t-test for comparing parental based mean differences on use of Behavioral disengagement. The results are found to be statistically significant at ($p < .01$) between the mother and Fathers of Down syndrome children.

Table 10 Means, Standard Deviations and t-values on Positive reframing between mother and father (N=100)

Variables	Father (n = 50)		Mother (n = 50)		t(98)	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Positive reframing	5.88	1.769	7.36	1.274	-4.801	.000	-2.09	-8.68	-0.96

Table 10 explains the results of t-test for comparing parental based mean differences on Positive reframing. The results are found to be statistically highly significant at ($p < .001$) between the mother and Fathers of Down syndrome children.

Table 11 Means, Standard Deviations and t-values on Planning between mother and father (N=100)

Variables	Father (n = 50)		Mother (n = 50)		t(98)	P	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Planning	6.10	1.67	6.82	1.71	-2.130	.036	-1.39	-.049	-0.43

Table 11 explains the results of t-test for comparing parental based mean differences on Planning. The results are found to be statistically significant at ($p < .05$) between the mother and Fathers of Down syndrome children.

Table 12 Means, Standard Deviations and t-values on Acceptance between mother and father (N=100)

Variables	Father (n = 50)		Mother (n = 50)		t(98)	P	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Acceptance	7.08	.94	7.46	1.31	-1.66	.100	-.83	.074	-0.33

Table 12 explains the results of t-test for comparing parental based mean differences on Acceptance. The results are found to be statistically non-significant at ($p > .05$) between the mother and Fathers of Down syndrome children.

Table 13 Means, Standard Deviations and t-values on Religion between mother and father (N=100)

Variables	Father (n = 50)		Mother (n = 50)		t(98)	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Religion	7.80	.94	7.50	1.30	1.85	.067	-0.87	.030	0.26

Table 13 shows the results of t-test for comparing parental based mean differences on Religion. The results are found to be statistically non-significant at ($p > .05$) between the mother and Fathers of Down syndrome children.

Table 14 Means, Standard Deviations and t-values on Self-blame between mother and father (N=100)

Variables	Father (n = 50)		Mother (n = 50)		t(98)	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Self-blame	6.44	1.643	7.40	1.355	-3.187	.002	-1.56	-.362	-0.64

Table 14 explains the results of t-test for comparing parental based mean differences on the use of Self-blame. The results is found to be statistically significant at ($p < .01$) between the mother and Fathers of Down syndrome children.

Table 15 Means, Standard Deviations and t-values on Humor between mother and father (N=100)

Variables	Father (n = 50)		Mother (n = 50)		t(98)	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Humor	5.38	2.184	6.74	1.78	-3.411	.001	-2.151	-.569	-0.68

Table 15 explains the results of t-test for comparing parental based mean differences on use of Humor. The results are found to be statistically -significant at ($p < .01$) between the mother and Fathers of Down syndrome children.

Table 16 Means, Standard Deviations and t-values on Stress between working and non-working parents (N=100)

Variables	Working (n = 68)		Non-Working (n = 32)		t	p	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Stress	54.00	5.64	58.7	4.70	-3.99	.000	-6.95	-2.337	-0.90

Table 16 shows the results of t-test for comparing working and non-working parents based mean differences on stress. The table shows that non-working parents of Down syndrome children have higher stress as compared to working parents of Down syndrome children. The mean difference 11.23 is highly significant between working and non-working of Down syndrome children.

Table 17 Means, Standard Deviations and t-values on brief coping and its subscales between working and non-working (N=100)

Variables	Working (n = 68)		Non- Working (n = 32)		t	P	95 %CI		Cohen's D
	M	SD	M	SD			LL	UL	
Brief Coping	92.54	15.89	103.8	9.77	-3.63	.000	-17.38	-5.08	-0.79
2. Self-distraction	7.18	1.14	7.55	1.150	-1.49	.138	-.865	.121	-0.32
3. Active coping	6.03	1.83	7.39	1.145	-3.80	.000	-2.06	-.649	-0.83
4. Denial	7.15	1.15	7.68	.832	-2.305	.023	-.987	-.074	-0.50
5. Substance use	7.09	1.194	7.77	.669	-2.98	.004	-1.142	-.230	-0.64
6. Use of emotional support	7.10	1.174	7.65	1.082	-2.183	.031	-1.035	-.049	-0.48
7. Use of instrumental support	6.31	1.831	6.94	1.28	-1.719	.089	-1.350	.097	-0.38
8. Behavioral disengagement	7.19	1.19	7.48	1.24	-1.123	.264	-.810	.225	-0.24
9. Venting	5.51	1.904	6.39	.989	-2.402	.018	-1.593	-.152	-0.53
10. Positive reframing	6.12	1.758	7.81	.654	-5.18	.000	-2.336	-1.041	-1.13
11. Planning	6.28	1.811	6.97	1.303	1.901	.060	-1.407	.030	-0.57
12. Humor	5.54	2.119	7.32	1.301	-4.310	.000	-2.59	-.960	-0.94
13. Acceptance	7.18	1.145	7.61	.844	-1.898	.061	-.893	.020	-0.41
14. Religion	7.15	1.149	7.74	.729	-2.65	.010	-1.041	-.149	-0.57
15. Self-blame	6.72	1.629	7.48	1.151	-2.35	.021	-1.407	-.119	-0.51

Table 17 shows the results of t-test for comparing the mean differences between working and non-working parents on brief coping and its subscales. The table shows that nonworking

parents of Down syndrome children have statistically significant higher means on active coping, denial, substance use, use of emotional support, venting, positive reframing, humor, religion and self-blame whereas on Self-distraction, Use of instrumental support, Behavioral disengagement, planning and acceptance means are statistically non-significant between working and non-working parents.

Discussion

These findings are consistent with international literature, which shows that mothers use a greater range of coping techniques than males due to their primary caregiving duties (Hastings & Taunt, 2002). The increased emotional engagement and time investment may explain why moms in this study scored much higher on both adaptive (e.g., active coping) and emotion-based methods.

Non-working parents, despite their improved availability, reported more stress and coping effort. This is consistent with research demonstrating that unemployment or remaining at home might increase social isolation, limit financial resources, and undermine psychological resilience (Seltzer et al., 2001). Nonworking parents' higher scores on both adaptive and maladaptive coping indicate that they may be using more techniques out of need rather than choice.

These trends demonstrate the interconnectedness of caring stress, gender norms, and socioeconomic stressors. In Pakistan, where gender roles are frequently inflexible and mental health resources are few, the findings highlight the importance of gender-sensitive therapies and occupationally inclusive family support models.

There is little question that caregivers of persons with Down syndrome (DS) experience significant levels of stress, given that DS is a lifelong disease and caregiver obligations grow as the person with DS ages. However, families and caregivers are progressively gaining personality traits and abilities that will be useful in adapting to their new living circumstances. The current study looked at the link between psychological capital, quality of life, and well-being of caregivers of people with Down syndrome.

The descriptive analysis revealed that participants reported high levels for all variables of PsyCap, well-being, and QoL. Statistical study revealed that three of the four dimensions of PsyCap are positively connected with QoL (self-efficacy, hope, and resilience, but not optimism), whereas just one factor (optimism) is associated with well-being—the direct impact, when considering the mediation analysis. QoL plays an important role in the links between self-efficacy, hope, resilience, and well-being, but not in the association between optimism and well-being. Overall, the benefits are favorable and significant, with QoL serving as a strong mediator in the association between PsyCap and well-being among caregivers/mothers of persons with SD.

These findings can be linked to the fact that caretakers successfully integrate their tasks in respect to the person with Down syndrome. The challenges presented by this condition encourage the development of qualities and abilities that contribute to personal growth and effective handling of stressful or crucial situations. Caregivers with high levels of self-efficacy, hope, and resilience may perceive a better-than-average quality of life and benefit from all of its components, including meaningful job, acceptable family connections, self-care time, and excellent health. Optimism and wellbeing. Overall, the benefits are favorable and significant,

with QoL serving as a strong mediator in the association between PsyCap and well-being among caregivers/mothers of persons with SD.

This positive perception of QoL leads to increased well-being, as caregivers are satisfied with their level of autonomy, control over the environment, the quality of interpersonal relationships, high levels of self-acceptance, personal growth, and, perhaps most importantly, consideration of the meaning of life. It should be mentioned that the participants are moms of individuals with Down syndrome. In a family with a member with Down syndrome, daily routines change, the house adapts, relationships and priorities shift, but in essence, life continues, and the obligations created by this scenario become actual problems that must be successfully faced.

Several studies found that moms of children with Down syndrome had higher levels of well-being and less strain than mothers of children with other intellectual impairments (Hodapp et al., 2001; Hodapp, 2002). The above-average outcomes for quality of life and well-being can be linked to marital status, with 81% of moms married and in a stable relationship. Previous research found that married couples divide care and duties, which can lead to improved well-being (Zajicek-Farber et al., 2015).

. Optimism was not significantly associated with QoL, which could be because QoL is a variable that refers to the individual's concrete living conditions, to how he or she lives his or her daily life, and optimism can diminish the pragmatic nuance of caregivers' existence, who have increased responsibilities in the family. In contrast, optimism is positively related with well-being, reflecting its subjective character. Well-being means a subjective perspective of the reality in which the individual lives his life; hence, optimism naturally leads to a better well-being, helping the caregiver to see life in a good way. Optimism contributes significantly to well-being since it predisposes the individual to take a positive approach to life's challenges.

. This study supports previous research indicating that moms of children with impairments use more coping methods than dads (Hastings & Taunt, 2002; Pisula & Porębowicz-Dörsmann, 2017). Mothers' higher scores on adaptive strategies such as active coping and planning, as well as emotion-focused methods like venting and positive reframing, indicate that they are more emotionally invested in caring and are more likely to seek social or internal stress management techniques. This is congruent with gender role expectations in many countries, including Pakistan, where mothers are frequently responsible for the care and emotional development of children with special needs (Pelchat et al., 2003).

Fathers, on the other hand, showed much lesser participation in coping techniques, which might be attributed to variations in societal expectations, job duties, and coping styles. Previous research has shown that dads may use avoidant or task-oriented coping strategies and are less likely to seek emotional support or express discomfort openly (Gray, 2003; Risdal & Singer, 2004). While such tactics may be culturally encouraged, they can also impede emotional processing and social support, potentially leading to unresolved stress. Pakistan, where mothers frequently bear major responsibility for the care and emotional development of children with special needs (Pelchat et al., 2003). Interestingly, non-working parents in this study reported much greater stress levels than working parents, despite having more time for caring. This contradiction might be explained by less social connection, financial uncertainty, and fewer organised daily routines, all of which have been linked to increased stress susceptibility (Seltzer et al., 2001). Non-working parents also used more adaptive and

maladaptive coping techniques, including as denial, substance use, and self-blame. These findings imply that the lack of job may exacerbate stress and need a larger coping repertoire, including ineffective techniques. Pelchat et al. (2003) examined the development of children with exceptional disabilities.

These findings highlight the complexities of caregiving in socioeconomically varied settings. In Pakistan, cultural beliefs and inadequate access to mental health services may exacerbate stress among non-working and solitary carers. The interaction of cultural norms, financial reliance, and gender roles results in diverse psychological effects that require tailored interventions.

Furthermore, this study demonstrates how job may function as both a stressor and a buffer. Working parents may face role pressure, but they also benefit from external social support networks, identity reinforcement, and economic security, all of which contribute to resilience (Hastings et al., 2005; Risdal and Singer, 2004). These issues should be addressed while developing carer support programs. In conclusion, the observed disparities highlight the importance of comprehensive, culturally relevant support systems that account for the diverse experiences of mothers and dads, as well as the various problems encountered by working and non-working parents. Improving emotional coping skills, fostering social involvement, and increasing access to mental health services are all important steps towards improving family well-being.

Implications for Practice:

- Create father-inclusive intervention programs that encourage emotional expression and active participation.
- Offer personalised mental health and peer support services to non-working carers.
- Encourage workplaces to implement family-friendly policies to accommodate parents with disabled children.

Conclusion:

This study adds to the expanding body of research on the psychological cost borne by parents of children with Down syndrome. It reveals considerable disparities in coping and stress depending on gender and work level. These findings should inform policy, program design, and family counselling practices aimed at promoting healthier, more resilient families.

Limitations:

- Cross-sectional design restricts causal inferences.
- Urban sample limits generalisability to rural regions.
- Social desirability bias can impact self-report measurements.

Future Recommendations:

- Longitudinal studies to track stress and coping over time.
- Qualitative research to capture complex parental experiences.
- Incorporating socio-economic status and family dynamics into future models.

Ethical Considerations: The University of Peshawar's ethical review committee authorised the research. All subjects provided informed consent. Data confidentiality and anonymity were rigorously enforced.

Conflict of Interest: The authors state that there is no conflict of interest linked with this work.

References:

- Alexander, M., Petri, H., Ding, Y., Wandel, C., Khwaja, O., & Foskett, N. (2016). Morbidity and medication in a large population of individuals with Down syndrome compared to the general population. *Developmental Medicine & Child Neurology*, 58(3), 246–254. <https://doi.org/10.1111/dmcn.12868>
- Areias, K., Cardoso, M., Pereira, M., & Fernandes, L. (2011). Burden and quality of life in caregivers of persons with Down syndrome. *Revista de Psiquiatria Clínica*, 38(6), 227–231.
- Bertrand, R. (2019). Well-being and caregiving: The impact of a positive outlook on the quality of life of caregivers of children with disabilities. *Journal of Health Psychology*, 24(1), 102–113.
- Bull, M. J. (2011). Health supervision for children with Down syndrome. *Pediatrics*, 128(2), 393–406. <https://doi.org/10.1542/peds.2011-1605>
- Carvalho, C., Santos, R., & Almeida, J. (2015). The challenges of aging in individuals with Down syndrome: A caregiver's perspective. *Aging & Mental Health*, 19(10), 937–944.
- Cuskelly, M., Hauser-Cram, P., & Van Riper, M. (2009). Families of children with Down syndrome: What we know and what we need to know. *Down Syndrome Research and Practice*, 12(3), 105–113.
- de Graaf, G., Buckley, F., & Skotko, B. G. (2020). Estimates of the live births, natural losses, and elective terminations with Down syndrome in the United States. *American Journal of Medical Genetics Part A*, 182(2), 446–463. <https://doi.org/10.1002/ajmg.a.61473>
- El-Gilany, A. H., Yahia, S. A., & Ibrahim, A. (2017). Burden among caregivers of children with Down syndrome in Mansoura, Egypt. *Egyptian Journal of Psychiatry*, 38(2), 72–77.
- European Commission Report. (2019). *Rare diseases: Understanding the challenges and opportunities*. European Union Publications Office.
- Ghosh, S., Feingold, E., & Dey, S. K. (2009). Etiology of Down syndrome: Evidence from population- and family-based studies. *Genetic Research International*, 2009, 1–12. <https://doi.org/10.1155/2009/608674>
- Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science & Medicine*, 56(3), 631–642.
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation*, 107(2), 116–127.
- Hastings, R. P., Kovshoff, H., Ward, N. J., Espinosa, F. D., Brown, T., & Remington, B. (2005). Systems analysis of stress and coping in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 35(5), 635–644.
- Henn, C. A., Piccinini, C. A., & Lopes, R. S. (2008). Caregiver stress and satisfaction in families of children with Down syndrome. *Revista Brasileira de Psiquiatria*, 30(1), 64–68.
- Hodapp, R. M. (2002). Parenting children with Down syndrome: Clues for research, directions for intervention. *International Review of Research in Mental Retardation*, 25, 195–218.
- Hodapp, R. M., Ricci, L. A., Ly, T. M., & Fidler, D. J. (2001). The effects of the child with Down syndrome on maternal stress. *British Journal of Developmental Psychology*, 19(3), 365–376.
- Jonsson, U., Olsson, N. C., & Broman, T. (2017). Psychiatric disorders in Down syndrome: A review. *Current Psychiatry Reports*, 19(6), 29.
- McCarron, M., McCallion, P., Fahey-McCarthy, E., & Connaire, K. (2018). Supporting persons with Down syndrome and advanced dementia: A care pathway perspective. *Journal of Policy and Practice in Intellectual Disabilities*, 15(1), 59–70.

- Pelchat, D., Lefebvre, H., & Perreault, M. (2003). Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability. *Journal of Child Health Care*, 7(4), 231–247.
- Pelchat, D., Lefebvre, H., & Perreault, M. (2003). Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability. *Journal of Child Health Care*, 7(4), 231–247.
- Pisula, E., & Porębowicz-Dörsmann, A. (2017). Family functioning, parenting stress and quality of life in mothers and fathers of Polish children with high functioning autism or Asperger syndrome. *PLOS ONE*, 12(10), e0186536.
- Pisula, E., & Porębowicz-Dörsmann, A. (2017). Family functioning, parenting stress and quality of life in mothers and fathers of Polish children with high functioning autism or Asperger syndrome. *PLOS ONE*, 12(10), e0186536.
- Risdal, D., & Singer, G. H. S. (2004). Marital adjustment in parents of children with disabilities: A historical review and meta-analysis. *Research and Practice for Persons with Severe Disabilities*, 29(2), 95–103.
- Risdal, D., & Singer, G. H. S. (2004). Marital adjustment in parents of children with disabilities: A historical review and meta-analysis. *Research and Practice for Persons with Severe Disabilities*, 29(2), 95–103.
- Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life course impacts of parenting a child with a disability. *American Journal on Mental Retardation*, 106(3), 265–286.
- Zajicek-Farber, M. L., Mayer, L. M., Daughtery, L., & Rodkey, E. N. (2015). Youth outcomes and maternal well-being in families of children with disabilities: A test of a transactional model. *Child & Adolescent Social Work Journal*, 32(2), 167–179.