

COMPASSION FATIGUE AS PREDICTOR OF MENTAL HEALTH OUTCOMES AMONG PARENTS OF CHILDREN WITH INTELLECTUAL DISABILITY

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Abstract

*The current study aims to investigate the relationship between compassion fatigue and mental health outcomes i.e. burnout and subjective wellbeing among parents of children with intellectual disability (ID). Based on the literature review, the following hypotheses were formulated: 1) There would be a positive relationship between compassion fatigue and burnout among parents of children with ID. 2) There would be a negative relationship between compassion fatigue and subjective well-being among parents with ID children. 3) There would be a predictive relationship of compassion fatigue with burnout and subjective wellbeing among parents of children with ID. A purposive sample of 200 parents of diagnosed children with intellectual disability was taken from special schools and different areas of Sialkot. A self-developed demographic sheet along with study scales were administered. For data analysis, descriptive and inferential statistics were applied. The results indicated that compassion fatigue has a significant positive relationship with burnout ($r = .67^{**}$, $p < .01$) and a negative relationship with LS ($r = -.33^{**}$, $p < .01$). Linear regression analysis showed that CF has significant potential to predict burnout ($R^2 = .45$, $p < .001$), and LS ($R^2 = .11$, $p < .001$). The current study will strengthen the understanding of the challenges associated with wellbeing and will suggest ways of improving family functioning and caregiver wellbeing ultimately to enlighten future research and interventions.*

Keywords Compassion Fatigue, Mental Health Outcomes, Burnout, Subjective wellbeing, Intellectual Disability

Introduction

Intellectual disability (ID) has been defined by the American Association on Intellectual and Developmental Disabilities (AAIDD), and the American Psychological Association (APA) as significant impairments in cognitive functioning (i.e. problem-solving, learning and reasoning) and daily living skills such as practical and social skills. As defined by the AAIDD, this disability required having its onset before the age of 18, and the assessment of this disability is based on multidimensional perspective (APA, 2023; AAIDD, 2023). This neurodevelopmental condition posed significant challenges for parents and often remained overlooked. Parenting a child with intellectual disabilities involved various difficulties, including emotional, practical, and social pressures which often went unnoticed and unaddressed (Scherer et al., 2019).

Compassion fatigue is a major factor for parents of children with intellectual disabilities (ID), defined as emotional and physical exhaustion resulting from continuous caregiving and exposure to others' suffering. This condition reduces the ability to empathize or feel compassionate, stemming from caregiving stress. It negatively impacts parents by diminishing their ability to nurture and provide for their children, thereby affecting the family's mental well-being (Baird & Kracen, 2024). Compassion fatigue is also recognized as secondary traumatic stress, exposing caregivers to distress linked with caregiving, leading to emotional disengagement as a coping mechanism (Jones & Smith, 2020; Perez et al., 2019). The emotional toll of compassion fatigue exacerbates the caregiver's involvement, leading to poor care quality as they become emotionally affected by the trauma of those they care for (Lopez et al., 2022). Davis and Thompson (2022) noted that compassion fatigue can lead to burnout when caregivers are overwhelmed and unable to care for patients, resulting in decreased empathy and self-care (Chen & Goh, 2020). This state, described as highly tiring, can cause negative mental health effects, as caregivers struggle to balance caring for others and themselves (Taylor et al., 2019).

Green et al. (2021) explained that compassion fatigue arises from chronic stress and worry, leading to fatigue, emotional withdrawal, and a reduced quality of life (Williams & Smith, 2017; Inan et al., 2018). Louw (2015) further emphasized that compassion fatigue results from overidentifying with the suffering of others, leading to overexertion and exhaustion. Caregivers often continue to give themselves completely to the patient, striving for a balance of empathy, objectivity, and engagement, which proves challenging. Parents of children with ID often feel a heavy sense of responsibility due to the demanding nature of their caregiving duties.

Burnout is a significant issue for parents, severely impairing their ability to care for their children. Caregiving often becomes an overwhelming burden, with emotional exhaustion leading to feelings of helplessness (Hansotte, 2021). This exhaustion causes psychological distancing from caregiving roles, resulting in impatience or negative feelings toward the tasks at hand. It is not just physical exhaustion but also emotional depletion that lowers caregiving standards (Glidden et al., 2021). Gajdzica (2023) described this as compassion fatigue, where caregivers become emotionally and physically overwhelmed, leading to feelings of incompetence and a lack of personal accomplishment. This condition is exacerbated when parents lack support, increasing their sense of helplessness (Findlings & Itzhaki, 2023).

Emam (2023) explained that burnout is a multidimensional process, involving physical, emotional, and cognitive responses to caregiving demands. The stress from unmet needs can lead to deteriorating mental health, making individuals more susceptible to depression and anxiety. It reduces emotional competency and impairs caregivers' ability to provide quality care. This also disrupts family relationships, adding to the caregiving stress (Martinez et al., 2021). Perez et al. (2023) noted that burnout creates a cycle of fatigue, emotional withdrawal, and feelings of inadequacy, which can cause long-term psychological distress and a decline in the caregiver's quality of life (Ochoa, 2023). As Perez et al. (2016) pointed out, burnout may not be transient but can lead to lasting impacts, emphasizing the need for addressing the underlying issues and providing adequate support. Mikolajczak and Roskam (2018) linked burnout to an imbalance between stress-producing and stress-buffering factors, resulting in negative changes in parent-child and family relationships. Parental burnout, a syndrome arising from chronic parental stress, includes symptoms like emotional exhaustion, detachment from children, and dissatisfaction with parenting. Parents experiencing burnout feel drained and disengaged, interacting with their children only to meet basic needs. These symptoms represent a shift from their previous attitudes toward parenting (Roskam et al., 2018; Roskam et al., 2017).

Subjective well-being is a dynamic process influenced by caregiver's circumstances and the support they receive (Patton et al., 2022). Zuna et al. (2019) emphasized that interventions to enhance well-being should focus on promoting resilience, encouraging social support, and addressing caregiving challenges. Seltzer (2020) highlighted the impact of personal factors like coping and resilience, and environmental factors such as social support and resource availability. Caregivers experiencing high levels of compassion fatigue or burnout tend to have lower well-being, as these phases negatively affect their emotional and psychological health (Parchomiuk, 2022). It is crucial in assessing mental health and how individuals respond to life experiences (Staunton et al., 2023). It is characterized by life satisfaction, positive affect, and the absence of negative emotions such as depression and anxiety (Shenaar, 2016). Parents of children with intellectual disabilities often struggle to maintain their well-being due to the demands of caregiving, with their well-being closely linked to caregiving resources and stress management (Werner et al., 2019). While subjective well-being involves a lack of negative feelings, it also includes having purpose and meaning in life, which can improve well-being if caregivers find meaning in their caregiving, despite the burdens (Yildiz et al., 2020).

According to estimations, the global prevalence of ID lies between 1% to 3% (Global Burden of Diseases, 2024; Seltzer et al., 2020). The prevalence was much higher in Pakistan with approximately 17%. In Australia, prevalence was stated to be about 1.7% (Bourke, 2016). In Ireland the prevalence was approximately 0.7% among children, with 65% of being male and mostly have mild to moderate disabilities (Department of Children and Youth Affairs, 2016). Globally, about 60% of people with ID from industrialized nations such as Australia, the US and the UK were being taken care of by their parents (Pryce et al., 2017). Research showed that the prevalence of compassion fatigue was present in 45% to 65% of caregivers of intellectually disabled children (Perry et al., 2017; Panicker & Ramesh, 2019). Llewellyn et al. (2017) noted that 60% of these parents were suffering from compassion fatigue and Zablotsky et al. (2019) noted moderate to high level of 48% showing that significant emotional strain in caregiving roles. Studies found that most of the parents of children with ID were experiencing compassion fatigue and burnout. Particularly, 67% exhibited moderate to high levels of compassion fatigue and 70% of burnout, and 65% poor Subjective Well-being (Ali & Aamir, 2018; Lauer & McCallion, 2015).

Researches on burnout revealed varied prevalence rates across different regions and contexts. In Europe 2%-12% of parents were found to suffer from parental burnout (Roskam et al., 2018). In Poland, 4% of parents stated this problem (Szczygiel et al., 2020). A global study found that burnout among parents in the general population ranged from 0% to 9% (Roskam et al., 2021). However, parents of with ID stated a high level of burnout with a considerable significance to low quality of life and emotional wellbeing (Grey, 2018; Ledoux, 2015). In Pakistan, burnout was observed in higher intensity with the caregivers having the lower socioeconomic status and limited support (Shahzad & Ali, 2021).

A study conducted by Panicker et al. (2019) in which, 72% of parents reported low subjective wellbeing and 60% had burnout symptoms with a positive correlation coefficient between low wellbeing and high burnout. On the other hand, Yildiz and Cavkaytar (2020) observed that only 40% of the parents with caregiving difficulties experienced moderate to high subjective wellbeing. Furthermore, Grace and Luckett (2020) found that 63% of the parents had moderate subjective wellbeing with the social support involving an aspect of parenting. In a broader sense, happiness score index of South Africa has been rated at 5.8, with Costa Rica taking the lead at 8.5 and Togo at the lowest with 2.6 (Van keer, 2018).

The findings showed that parents of children with intellectual disabilities had a higher level of burnout and psychological distress because of higher caregiving stress and lower social support (Ryan & Quinlan, 2018). Through intended and unintended interaction with the stress

and demands of caregiving, parents are prone to high level stress, anxiety and depression. In addition, the long-term nature of most caregiving roles can worsen feelings of caregiver fatigue and therefore has a negative impact on wellbeing (Mäkikangas & Kinnunen, 2016). The parents of these children with ID suffered from burnout and compassion fatigue because of many reasons. These include the severity of the child's disability, economic resources, lack of social support and availability and utilization of caregiving resources. These contributed to the parent's stress and emotional exhaustion while managing for their children with intellectual disabilities (Barnard and Curry, 2016). Even compassion fatigue directly affects the subjective wellbeing of caregivers. The study by Perry et al. (2017) revealed that parents experiencing compassion fatigue have negative emotional experiences, reduced positive affect and quality of life. The studies on the relationship between the wellbeing of parents of children with ID and their stress level showed that parental stress caused decreased overall subjective wellbeing of parents and increased burnout levels. Due to high demands and various stressors related to caregiving alongside the absence of socialization and emotional engagement, parents usually suffered from diminished wellbeing according to various research, including the one performed on Pakistani parents solely (Khan, 2020).

Research by Totsika & Hastings (2017) delved into examining the parental stress and psychological distress of those parents who have children with intellectual disabilities. Furthermore, research found that the parents who seemed their partner as involved in the caregiving tasks reflected the decreased level of perceived psychological distress (Song & Floyd, 2020). Moreover, studies revealed that when parents reported low levels of parental mutuality, they exhibited high burnout with poor subjective well-being and quality of life in parents having a child with ID in Pakistan; mental health difficulties were higher in families having no or little emotional and social support (Hansotte et al., 2021). Also, a study found that the extensivity of inter-parental relationships and the visions regarding the future of the child influenced the formation of burnout symptoms (Demirhan et al., 2011). In the study by Wang and colleagues (2017) family and social support enhanced the life satisfaction of parents with children with ID which enabled the parents to deal with caregiving challenges and avoid mental health problems. Higher levels of subjective wellbeing increased their positive psychological states, satisfaction and happiness while lower levels reduced their levels of stress and perceived unhappiness and negativity about their children (Rakhman et al., 2018). Collings et al. (2017) found that parents often experienced difficulty, pressure and stress which leads to unpleasant feelings and lower wellbeing. Furthermore, families of children with intellectual disabilities had lower wellbeing because they faced more financial stress (Griffith & Hastings, 2018).

Study showed a significant relationship between compassion fatigue, burnout and subjective wellbeing of parents of children with intellectual disabilities. Durling et al. (2018) pointed out that compassionate fatigue leads to enhanced burnout, this had a negative impact and reduced wellbeing. It was also positively associated with burnout levels as a consequence of compassion fatigue to extend for a longer period. Cin and Aydın (2017) study found that parents of disabled children had experienced significantly higher levels of burnout. This could lead to self-blame, a sense of failure, a lack of ability to handle problems, and require more self-support in many areas of their lives than what they need to raise healthy children. These parents needed more support than normal parents raising healthy children which strained family relations and their standard of living. They often sought comprehensive support in various aspects of their lives (Pérez-Cruzado & Cuesta-Vargas, 2016). Stress caused burnout in parents and couples and children had problems like suicidal thoughts, marital conflict, neglect and illnesses (Mikolajczak et al., 2018). Furthermore, families having more than one child with the special need or any comorbidity found a higher level of burnout which leads to poor wellbeing in all areas of life for the families (Gerain & Zech, 2018).

The research found that the parents of children with special needs experienced relatively high levels of happiness when the positive relationships involved the child's education and they felt significance in their parenting role. In the same regard, Perdana and Dewi (2015) opined that parental satisfaction resulted from parental acceptance of the child with special needs and that providing care to such a child supersedes all other obligations in their life (Faisal & Hermina, 2019). The study showed that high levels of compassion fatigue was associated with low levels of support and understanding of the parent-child relationship affecting the parents' overall well-being (Blair & Perry, 2017). Subjective wellbeing increased due to social support. High levels of perceived partner support and strong social networks increased life satisfaction and can buffer the adverse impact of caregiving (Hwang, 2016). Compassion fatigue reduced the wellbeing. Stress and burnout were decreased (Beighton & Wills, 2019). Parent associated difficulties were focused on social support which needed to be increased to avoid issues or manage them to have positive effects on the quality of family life (Misura & Memisevic, 2017).

Following hypotheses have been formulated for the current study:

1. There would be a positive relationship between compassion fatigue and burnout among parents of children with ID.
2. There would be a negative relationship between compassion fatigue and subjective well-being (PA, NA, and LS) among parents of children with ID.
3. There would be a predictive relationship of compassion fatigue with burnout and subjective wellbeing among parents of children with ID.

Method

Research Design

A cross sectional correlational study design was used to assess the relationship of compassion fatigue with mental health outcomes among parents of children with intellectual disabilities.

Sample

A sample of 200 parents of diagnosed children with intellectual disability as per Diagnostic Manual of Mental Disorders (APA, 2023) was taken through purposive sampling from different special education schools/institutes of Sialkot and nearby Sialkot. They were equal in number i.e., 100 fathers and 100 mothers. Their age range was between 25-50 years. The minimum level of education was matriculation and they belonged to lower, middle and upper socioeconomic status with both nuclear and joint family setups.

Assessment Measures

Self-Develop Demographic Sheet

Demographic variables comprised of i.e.; name, age of child, age of parents, education level of parents, duration of marriage, No. of children, family setup, occupation of father and mother, earning members and monthly income. What are the thoughts, feelings, and emotions experienced by parents in relation to having a diagnosed intellectually disabled child? Are there any support systems available for parents dealing with a child who has intellectual disability?

Compassion Fatigue and Burnout subscales of Professional Quality of Life Scale (Stamm, 1995)

The scale consists of 30 items, categorized into three sub-scales each consists of 10 items. For the current study, only the "burnout" and "compassion fatigue" subscale was used. Compassion fatigue on items (2,5,7,9,11,13,14,23,25,28) and burnout on items (1,4,8,10,15,17,19,21,26,29). The reverse items are 1, 4, 15, 17, and 29. The subscales of burnout and compassion fatigue were adapted as per our study requirement and translated into Urdu. This scale has been widely used with parents, it assesses both positive and negative impacts of aiding those undergoing suffering and trauma. The ProQOL 5 measure allows for

the substitution of the term "helper" with an appropriate term for the target group used. For this study, the term "helper" was substituted with "parent" to measure compassion fatigue and burnout among parents as the previous researches have demonstrated in their studies of (Davenport & Zolnikov, 2022; Lynch, Shuster et al., 2018). Each item measures how frequently a respondent has experienced symptoms in the past 30 days on a 5-point Likert scale (1 =never to 5= very often), with an alpha reliability of 0.81. The Cronbach's alpha values for the subscales of burnout and compassion fatigue are 0.75 and 0.81.

ICP Subjective Well-being Scale (Moghal and Khanam, 2013)

Moghal and Khanam (2013) developed the ICP Subjective Well-being Scale, comprising three subscales: positive affect (PA), negative affect (NA) and life satisfaction (LS). The scale consists of 12 items for PA, 12 for NA, and 5 for LS, with responses recorded on a 5-point Likert scale. The Urdu version of the scale was used. Test-retest reliability ranges from 0.73 to 0.82, and the reliability (Cronbach alpha) is 0.80 to 0.84. The scale is validated and proven effective for assessing cognitive and affective well-being.

Procedure

First of all permission was taken from the authorities of the special institutes and schools for data collection and information about the parents of intellectually disabled children was gathered from these institutions. Additionally, schools were asked if parents of children with ID could be contacted at the school to collect the necessary information or data. Participants were provided with an informed consent form along with the demographic sheet and scales including Compassion Fatigue subscale and Burnout subscale of Professional Quality of Life scale (Stamm, 1995) and ICP Subjective Well-being Scale (Moghal and Khanam, 2013). After data collection further statistics analysis was applied.

Ethical considerations

First of all, approval from different statutory bodies was obtained. Permission to use the scales for the study was obtained from their authors of the scales, followed by approval from the authorities of the special institutes and schools for data collection. Participants were then approached and written consent was taken from them. Queries from participants regarding the questionnaires were addressed, and they were assured that their responses would remain confidential. Participants were allowed to withdraw from the study at any stage.

Statistical Analyses

Data was analyzed using the Statistical Package for Social Sciences (SPSS) version 25. For data analysis, mean and standard deviation were computed through descriptive analysis. Pearson Product Moment Correlation Coefficient was used to assess relationships, and Linear Regression Analysis was conducted for predictive relationships.

Results

The main statistical findings of the current data are being presented in this section. To analyze the data of Descriptive statistics, Pearson Product Correlation coefficient, Linear Regression Analysis were applied by using a statistical package used for social sciences (SPSS, 25).

Table 1

Summary of Socio-Demographic and Characteristics of the Sample

Variables	n	%
Parent		
Father	100	50.0
Mother	100	50.0
Child gender		
Male	134	67.0
Female	66	33.0
Age Groups of Child		

5-8	70	35.0
9-11	60	30.0
12-14	28	14.0
15-18	42	21.0
Age Groups of Mother		
25-30	26	13.0
31-35	62	31.0
36-40	40	20.0
41-45	46	23.0
46-50	26	13.0
Age Groups of Father		
25-30	17	8.5
31-35	22	11.0
36-40	56	28.0
41-45	54	27.0
46-50	51	25.5
Education level of Mother		
Matriculation	94	47.0
Intermediate	40	20.0
Graduation	66	33.0
Post Graduation	0	0
Education level of Father		
Matriculation	96	48.0
Intermediate	52	26.0
Graduation	42	21.0
Post Graduation	10	5.0
Occupation of Mother		
Employed	18	9.0
Unemployed	182	91.0
Occupation of Father		
Employed	200	100.0
Unemployed	0	0
Duration of Marriage		
5-9	22	11.0
10-14	64	32.0
15-19	46	23.0
20-24	46	23.0
25-30	22	11.0
No. of Children		
1-3	108	54.0
4-5	92	46.0
Family set up		
Joint	94	47.0
Nuclear	106	53.0
Earning Members		
1	146	73.0
2	24	12.0
3	30	15.0
Monthly income		
Less than 50,000	122	61.0

51,000 to 10,0000	64	32.0
10,1000 and above	14	7.0
Support system available		
Yes	42	21.0
No	158	79.0
Specify if any		
Grandparents	23	11.5
Uncle/aunt	11	5.5
House help/maid	8	4.0
<i>N=200</i>		

Note: According to the above table, there are 200 parents of ID children with an equal representation of fathers (50%) and mothers (50%). Among the children, 67% are male. The majority of children fall into the 5-8 age group (35%). In terms of parental age groups, most mothers are in the 31-35 range (31%), while the majority of fathers fall in the 36-40 range (28%). Regarding education, the majority of fathers (48%) and mothers (47%) have completed matriculation studies. All fathers are employed (100%), while 91% of mothers are unemployed. The most common duration of marriage is 10-14 years (32%). Most families live in a nuclear setup (53%), with a majority having one earning member (73%). Regarding monthly income, 61% of families earn less than 50,000. Most of the families do not have any support system (79%) but among those who do have grandparents, are the most common form of support.

Table 2

Descriptive Statistics and Cronbach's Alpha of all the Scales and Subscales (N=200)

Scales and Subscales	No. of Items	<i>M</i>	<i>SD</i>	<i>Sk</i> ^a	<i>Ku</i> ^b	<i>α</i>
Compassion Fatigue (CF)	10	27.46	9.26	.00	-.93	.88
Burnout (BO)	10	26.73	6.85	-.25	-.42	.73
Positive Affect (PA)	12	41.02	7.27	-.12	-.78	.71
Negative Affect (NA)	12	40.96	7.27	.12	-1.04	.71
Life Satisfaction (LS)	5	16.07	4.43	-.25	-.54	.79

^a Standard error of skewness =.17, ^b Standard error of Kurtosis =.34

Table 3

Pearson Product Moment Coefficient of Correlation of Compassion Fatigue (CF) with Burnout (BO) and Subjective wellbeing (Positive Affect (PA), Negative Affect (NA), Life Satisfaction (LS) Variables (N= 200)

Variables	<i>M</i>	<i>SD</i>	1	2	3	4	5
1. Compassion Fatigue	27.46	9.26	-	.67**	.06	.02	-.33**
2. Burnout	26.73	6.85		-	.09	.14*	-.45**
3. Positive Affect	41.02	7.27			-	.76**	.11
4. Negative Affect	40.96	7.27				-	-.00
5. Life Satisfaction	16.07	4.43					-

Note: Findings of the above table reveal that compassion fatigue shows a significant strong positive correlation with burnout ($r = .67^{**}$, $p < .01$). Analysis further reveals that compassion fatigue has a significant negative mild correlation with the subscale of subjective wellbeing i.e. life satisfaction ($r = -.33^{**}$, $p < .01$) whereas it does not have significant correlations with the other subscales i.e. PA ($r = .06$, $p > .05$) or NA ($r = .02$, $p > .05$).

Table 4

Linear Regression Analysis of Compassion Fatigue and Burnout (N=200)

Variables	<i>B</i>	<i>SE</i>	β	<i>t</i>	<i>p</i>	<i>R</i> ²	ΔR	<i>F</i>
Constant	12.99	1.12		11.58	.000	.45	.45	167.34

Compassion Fatigue	.50	.03	.67	12.93	.000
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Note: The results of the linear regression analysis indicated that compassion fatigue has the potential to predict burnout. The R^2 value of .45 revealed that the predictor variable explained 45% variance in the outcome variable with $F(1,198) = (167.35, p < .001)$. Compassion fatigue ($B = .50, p < .001$) has a statistically significant effect on burnout which means that 1 unit increase in CF would bring .50 times increase in dependent variable, which shows that compassion fatigue has the potential to bring 50% change in burnout scores.

Table 5

Linear Regression Analysis of Compassion Fatigue and Positive Affect (N=200)

Variables	B	SE	β	t	p	R^2	ΔR	F
Constant	39.58	1.61		24.55	.000	.00	-.00	.89
Compassion Fatigue	.05	.05	.67	.94	.346			

Note: The results of the linear regression analysis indicated that compassion fatigue did not significantly predict positive affect, $F(1,198) = .89, p > .05$, explaining no variance in positive affect ($R^2 = .00$). CF ($B = .05, p > .05$) does not have the potential to predict PA.

Table 6

Linear Regression Analysis of Compassion Fatigue and Negative Affect (N=200)

Variables	B	SE	β	t	p	R^2	ΔR	F
Constant	40.45	1.61		25.03	.000	.00	-.00	.11
Compassion Fatigue	.01	.05	.02	.33	.738			

Note: The results of the linear regression analysis indicated that compassion fatigue did not significantly predict negative affect, $F(1,198) = .11, p > .05$, explaining no variance in negative affect ($R^2 = .00$). CF ($B = .01, p > .05$) does not have the potential to predict NA.

Table 7

Linear Regression Analysis of Compassion Fatigue and Life satisfaction (N=200)

Variables	B	SE	β	t	p	R^2	ΔR	F
Constant	20.49	.92		22.06	.000	.11	.10	25.19
Compassion Fatigue	-.16	.03	-.33	-5.02	.000			

Note: The results indicated that compassion fatigue has the potential to predict life satisfaction. The R^2 value of .11 revealed that the predictor variable explained 11% variance in the outcome variable with ($F(1,198) = 25.19, p < .001$). CF ($B = -.16, p < .001$) has a statistically significant effect on LS indicating that 1 unit increase in CF would bring -.16 times decrease in the dependent variable which shows that CF has the potential to bring 16% change in LS scores.

Discussion

This part focuses on the findings of current study regarding compassion fatigue (CF) and mental health outcomes; burnout (BO) and subjective wellbeing (SWB) (positive affect (PA), negative affect (NA) and life satisfaction (LS)) among parents of children with ID. The whole explanation is based on the theoretical framework and recently conducted researches. The current research hypothesized that compassion fatigue has a positive correlation with burnout and a negative correlation with subjective well-being (PA, NA and LS) among parents of ID children.

The results revealed that compassion fatigue had a significant positive correlation with burnout. The reasons behind this, as it has been observed by researcher that parents get emotionally overwhelmed from caregiving demands like managing the child or any other needs of the child without proper rest. Lack of personal space or self-care enhanced emotional exhaustion and this was intensified by stress arising from unresolved caregiving demands.

Gradually, symptoms of compassion fatigue were expressed physically and mentally like of constant feeling of fatigue, anxiety and recurrent illness leads to signs of burnout. Moreover, the parents reported loneliness and lack of social support from family members which heightened the burnout more owing to lack of support as they felt ignored and overwhelmed.

Previous studies and theory are in line with the current findings i.e. the findings are well backed by Vicarious Trauma Theory (Figley, 1995) which posited that persons who often witnessed other people's trauma could also be traumatized in a similar way as persons who underwent through trauma themselves. Parents of children with ID witnesses their child's daily difficulties and suffering which consequently caused secondary trauma. This trauma drained them emotionally hence developing compassion fatigue. This depletion led to stress, exhaustion and ultimately leads to burnout. As a previous study by Masulani et al. (2016) revealed that compassion fatigue had a positive impact on burnout among caregivers of special needs children thus supporting the current research's findings. Nam and Park (2017) have highlighted the fact that better levels of CF were linked to increased levels of BO. Furthermore, Pryce et al. (2017) pointed out that burnout was experienced due to chronic stress and emotional exhaustion from caregiving which is in line with the findings shown in this research.

The findings revealed that compassion fatigue had a negative effect on LS. The reasons behind this, as it has been observed by researcher that the parents in the study who had compassion fatigue did not derive pleasure from activities as they used to once enjoyed. Reduced social integration such as social isolation, conflict with others, lack of interest in intimate relationships and irritability also leads to low life satisfaction. Hopelessness and worthlessness negated positive aspects of living while lack of attention to self and individual needs lower the quality of life. Also, reduced chances of leisure because of the always occupied caregiving roles was also a reason for the tumble-down life satisfaction.

The findings were well supported by Hedonic Well-being Theory (Diener, 1984) explored aspects of well-being by focusing on the presence or absence of pleasure and negative emotions. By reducing the amount of emotional capacity and increasing feelings of distress and discomfort compassion fatigue supposedly negatively affect the capacity to experience pleasure. When parents experiencing compassion fatigue were unable to find meaning and be happy, or manage suffering, their life satisfaction was affected. This was in line with the theory that posited that decreased pleasure alongside increased emotional pain resulted to lower life satisfaction. Singh et al. (2020) previously reported that high levels of compassion fatigue led to difficulties in achieving life satisfaction due to ongoing emotional and psychological strain. Similarly, Misura and Memisevic (2019) found that compassion fatigue hindered parent's ability to engage in positive activities and experience a sense of accomplishment thereby reducing life satisfaction. These prior research correlate with this study's results wherein it revealed that as compassion fatigue rises LS declines.

It is also vital to note that these results showing no significant difference, are also supported by recent research findings of PA and NA. The reasons behind this, as it has been observed by researcher that the stress coming from compassion fatigue may continue to elicit negative emotions and yet PA and NA may not change all that much. The common strain and load of care responsibilities kept the fluctuations of both PA and NA relatively small. Stress and emotional exhaustion led to constantly depersonalized and distressed emotional experience while there were no significant fluctuations in the general affective states. The findings were underpinned by the Stress Process Framework (Adams et al., 2006; Figley, 2002) which describes how chronic stressors influence emotional conditions. It is understandable that caregiving stress if unrelieved remains constantly negative while there is inadequate evidence to show that even caregiving resources and support resources can switch the balance of PA and NA. This led to more or less a constant level of stress without a significant change in the mood.

As a previous study by Blacher et al., (2018) noted that while life satisfaction and stress decreased among caregivers of ID children their positive affect did not reduce and suggested that support and coping strategies may protect against such effects. The current study revealed that parents of intellectually disabled children reported high levels of compassion fatigue, positive affect did not change significantly. However, it argued that resilience and support systems might help to sustain the positive affect (Smith et al., 2018). Moreover, in another study no relation was observed in which compassion fatigue was not associated with negative affect in parents of ID children. They proposed that negative affect might be more related with the caregiving stress and burden rather than compassion fatigue and this aligned with the study results (Mendes et al., 2016). Perry et al. (2021) revealed that compassion fatigue was not directly related to negative affect. Their study emphasized that daily stressors and caregiving demands had a stronger association with negative affect.

The second hypothesis has highlighted the predictive relationship between CF with BO and subjective wellbeing among parents of ID children.

The results indicated that compassion fatigue was a significant positive predictor of burnout. The reasons behind this, as it has been observed by researcher that parents experienced chronic guilt or inadequacy as they thought they were not providing enough care for the child with IDs. This emotional load accumulated in chronic stress throughout the years. The lack of a definable timeline for caregiving further created a feeling of entrapment that in turn amplified emotional exhaustion. Also, since the situation with children did not change for the better and fear of constant deterioration emerged thus, parents experienced burnout. The study was underpinned by Stress-Appraisal Theory of Lazarus and Folkman (1984) that parents of children with ID might consider the load of caregiving beyond their capacity to cope. Thus, this constant evaluation of the guilt and inadequacy and the permanency of their child's disability resulted in chronic stress and emotional exhaustion that resulted in burnout. The findings were supported by previous studies which established that high levels of compassion fatigue did correlate with high level of burnout among parents who care for ID children (Singal, 2016). Similarly, Grey et al. (2018) noted that compassion fatigue had a direct association between burnout in caregiving roles and the mental health of the caregivers.

The results showed that compassion fatigue was a significant negative predictor of LS. As predicted, there was negative relationship between CF and LS. The reasons behind this, as it has been observed by researcher that CF impacted the quality of life since parents experienced inadequacy, lack of accomplishment and always sensed stressed. The results were underpinned by Theory of Subjective Wellbeing Homeostasis (Cummins, 2009) that people have their general state of wellbeing despite the level of stress in the environment. compassion fatigue, which reduced overall life satisfaction brought imbalance. Williams and Porter (2017) reported that compassion fatigue reduced the caregiver's life satisfaction negating the aspect of wellbeing.

References

- Adams, R. E., Boscarino, J. A., & Figley, C. R. (2006). Compassion fatigue and psychological distress among social workers: A validation study. *American Journal of orthopsychiatry*, 76(1), 103-108. <https://doi.org/10.1037/0002-9432.76.1.103>
- Aktan, O., Orakçı, Ş., & Durnalı, M. (2020). Investigation of the relationship between burnout, life satisfaction and quality of life in parents of children with disabilities. *European Journal of Special Needs Education*, 35(5), 679-695. <https://doi.org/10.1080/08856257.2020.1748429>

- Allday, R. A., Newell, J. M., & Sukovskyy, Y. (2020). Burnout, compassion fatigue and professional resilience in caregivers of children with disabilities in Ukraine. *European Journal of Social Work*, 23(1), 4-17. <https://doi.org/10.1080/13691457.2018.1499611>
- American Association on Intellectual and Developmental Disabilities. (2023). *Intellectual disability: Definition, classification, and systems of supports* (12th ed.). AAIDD.
- American Psychiatric Association. (2023). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.). American Psychiatric Publishing
- Baird, K., & Kracen, A. C. (2024). Vicarious traumatization and secondary traumatic stress: A research synthesis. *Counselling Psychology Quarterly*, 19(2), 181-188. <https://doi.org/10.1080/09515070600811899>
- Barnard, L. K., & Curry, J. F. (2012). The relationship of clergy burnout to self-compassion and other personality dimensions. *Pastoral Psychology*, 61, 149-163. <https://doi.org/10.1007/s11089-011-0377-0>
- Beighton, C., & Wills, J. (2019). How parents describe the positive aspects of parenting their child who has intellectual disabilities: A systematic review and narrative synthesis. *Journal of Applied Research in Intellectual Disabilities*, 32(5), 1255-1279. <https://doi.org/10.1111/jar.12617>
- Blacher, J., Begum, G. F., Marcoulides, G. A., & Baker, B. L. (2018). Longitudinal perspectives of child positive impact on families: Relationship to disability and culture. *American Journal on Intellectual and developmental disabilities*, 118(2), 141-155. <https://doi.org/10.1352/1944-7558-118.2.141>
- Bourke J, de Klerk N, Smith T, et al. (2016) Population-based prevalence of intellectual disability and autism spectrum disorders in Western Australia: A comparison with previous estimates. *Medicine (Baltimore)* 95: e3737. <https://doi.org/10.1016/j.jpeds.2017.06.008>
- Bowen, M. (1978). *Family therapy in clinical practice*. New York, NY: Aronson.
- Bronfenbrenner, U. (1979). The ecology of human development: Experiments by nature and design. *Harvard University Press google schola*, 2, 139-163.
- Chen, X., & Goh, C. (2020). The role of parental mutuality in mitigating the effects of caregiving stress on the mental health of parents of children with intellectual disabilities. *Journal of Family Psychology*, 34(6), 775-785. doi: 10.1007/s10995-016-2136-4.
- Cin, F. M., M. A. Aydın, and E. Arı. 2017. "Zihinsel Engelli Bireye Sahip Olan Ebeveynlerin Tükenmişlik Düzeylerinin İncelenmesi (Examining Burnout Levels Of Mentally Disabled Children's Parents)." *İstanbul Ticaret Üniversitesi Sosyal Bilimler Dergisi* 16 (31): 19–32. <https://doi.org/10.1080/08856257.2020.1748429>
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98(2), 310-357. <https://doi.org/10.1037/0033-2909.98.2.310>
- Collings, S., Grace, R., & Llewellyn, G. (2017). The role of formal support in the lives of children of mothers with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 492-500. <https://doi.org/10.1111/jar.12361>
- Cummins, R. A. (2013). Limitations to Positive Psychology Predicted by Subjective Wellbeing Homeostasis. In M. L. Wehmeyer (Ed.), *Oxford Handbook of Positive Psychology and Disability*. New York: Oxford University Press (in press). https://doi.org/10.1007/978-94-007-2421-1_4
- Davis, R. E., & Thompson, L. M. (2022). Compassion fatigue among parents of children with intellectual disabilities: A review of recent literature and implications for future

- research. *Journal of Child and Family Studies*, 31(2), 322-335. Doi: 10.1002/ajmg.a.38508.
- Demirhan, E., İçağasioğlu, A., Eriman, E. Ö., Tezel, C. G., Baklacioğlu, H. Ş., Haliloğlu, S., & Aras, H. (2011). BURNOUT OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY. *Nobel Medicus Journal*, 7(3). doi: 10.1111/famp.12379
- Diener, E., & Lucas, R. E. (2000). Subjective emotional well-being. *Handbook of emotions*, 2, 325-337.
- Durling E, Chinn D and Scior K (2018) Family and community in the lives of UK Bangladeshi parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 31(6): 1133–1143. <https://doi.org/10.1111/jar.12473>
- Emam, M. M., Al-Hendawi, M., & Gaafar Ali, D. (2023). Parenting stress and life satisfaction in families of children with disabilities: the mediating effect of social support in three Arab speaking countries. *Journal of Family Studies*, 29(1), 134-152. <https://doi.org/10.1080/13229400.2021.1893791>
- Figley, C. R. (1995). Compassion fatigue: Toward a new understanding of the costs of caring.
- Figley, C. R. (1995). Systemic traumatization: Secondary traumatic stress disorder in family therapists. <https://doi.org/10.1037/10172-033>
- Findling, Y., Barnoy, S., & Itzhaki, M. (2023). “God gave you a special child because you are special”: difficulties, coping strategies, and parental burnout of Jewish mothers—a qualitative study. *Frontiers in Psychology*, 14, 1259670. <https://doi.org/10.3389/fpsyg.2023.1259670>
- Gajdzica, Z., Byra, S., Kołodziej-Zaleska, A., Rutkowska, K., & Dzienniak-Pulina, D. (2023). *Mental Health and Quality of Life of Adolescents with Physical, Intellectual and Developmental Disabilities: Perspectives of Parents and Children*. Routledge. <https://doi.org/10.4324/9781003367772>
- Gérain, P., & Zech, E. (2018). Does informal caregiving lead to parental burnout? Comparing parents having (or not) children with mental and physical issues. *Frontiers in psychology*, 9, 884. <https://doi.org/10.3389/fpsyg.2018.00884>
- Glidden, L. M., Floyd, F. J., Hastings, R. P., & Mailick, M. R. (2021). Family impact and adjustment across the lifespan: *Parents of children with intellectual and developmental disabilities*. doi:10.1037/0000195-009
- Grace, R., & Lockett, T. (2020). Subjective well-being in parents of children with disabilities: A systematic review. *Disability and Health Journal*, 13(3), 100929. doi: 10.1016/j.pedn.2018.12.007
- Green, S. E., Darling, R. B., & Wilbers, L. (2023). Has the parent experience changed over time? A meta-analysis of qualitative studies of parents of children with disabilities from 1960 to 2012. *Disability and intersecting statuses*, 7, 97-168. [https://doi.org/10.1108/S1479-3547\(2013\)0000007007](https://doi.org/10.1108/S1479-3547(2013)0000007007)
- Grey, J. M., Totsika, V., & Hastings, R. P. (2018). Physical and psychological health of family carers co-residing with an adult relative with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 31, 191-202. <https://doi.org/10.1111/jar.12353>
- Griffith, G. M., Hastings, R. P., Nash, S., Petalas, M., Oliver, C., Howlin, P., ... & Tunnicliffe, P. (2011). “You have to sit and explain it all, and explain yourself.” Mothers’ experiences of support services for their offspring with a rare genetic intellectual disability syndrome. *Journal of Genetic Counseling*, 20, 165-177. <https://doi.org/10.1007/s10897-010-9339-4>

- Hansotte, L., Nguyen, N., Roskam, I., Stinglhamber, F., & Mikolajczak, M. (2021). Are all burned out parents neglectful and violent? A latent profile analysis. *Journal of Child and Family Studies*, 30, 158-168. <https://doi.org/10.1007/s10826-020-01850-x>
- Hwang, Y. S., & Singh, N. N. (2016). Mindfulness. *Handbook of evidence-based practices in intellectual and developmental disabilities*, 311-346.
- Inan Budak, M., Küçük, L., & Civelek, H. Y. (2018). Life experiences of mothers of children with an intellectual disability: A qualitative study. *Journal of Mental Health Research in Intellectual Disabilities*, 11(4), 301-321. <https://doi.org/10.1080/19315864.2018.1518502>
- Jones, L., & Smith, A. (2020). Compassion fatigue in parents of children with chronic illnesses: Identifying the sources and mitigating strategies. *Journal of Family Therapy*, 42(1), 45-59. doi: 10.1590/0104-1169.2978.2379
- Khan, S. (2020). Stress in the patients of Children with Physical Disability. *Interaction*, 79(16), 30. DOI: 10.57197/JDR-2024-0052
- Lazarus, R. S. (1984). *Stress, appraisal, and coping* (Vol. 464). Springer.
- Llewellyn, N. W., Wade, C., & Man, G. (2017). Prevalence of parents with intellectual disability in Australia. *Journal of Intellectual and Developmental Disability*, 42(2), 173–179. <https://doi.org/10.3109/13668250.2016.1218448>
- Lopez, C. M., Green, K., & Lambert, J. E. (2022). Compassion fatigue and its impact on parental mental health: An exploration of contributing factors. *Journal of Family Therapy*, 44(3), 490-504. doi: 10.1590/S1980-220X2017048703377
- Louw, D. (2015). Compassion fatigue: Spiritual exhaustion and the cost of caring in the pastoral ministry. Towards a 'pastoral diagnosis' in caregiving. *HTS: Theological Studies*, 71(2), 1-10. <https://hdl.handle.net/10520/EJC179694>
- Mäkikangas, A., & Kinnunen, U. (2016). The person-oriented approach to burnout: a systematic review. *Burnout Research*, 3, 11–23. <https://doi.org/10.1016/j.burn.2015.12.002>
- Martinez, A. R., Taylor, M., & Gomez, P. (2023). The long-term effects of compassion fatigue on parents of children with disabilities. *Journal of Developmental Disabilities*, 39(2), 150-163 <https://doi.org/10.3390/soc13050131>
- Maslach, C., & Jackson, S. E. (1981). The measurement of experienced burnout. *Journal of organizational behavior*, 2(2), 99-113. <https://doi.org/10.1002/job.4030020205>
- Masulani MC, Mathanga D, Silungwe D, et al. (2016) Parenting children with intellectual disabilities in Malawi: The impact that reaches beyond coping? *Child: Care, Health & Development* 42(6): 871–880. <https://doi.org/10.1111/cch.12368>
- Mendes, T. P. G. P., Crespo, C. A. M., & Austin, J. K. (2016). Family cohesion and adaptation in pediatric chronic conditions: The missing link of the family's condition management. *Journal of Child and Family Studies*, 25, 2820-2831. <https://doi.org/10.1007/s10826-016-0447-0>
- Mikolajczak, M., Brianda, M. E., Avalosse, H., & Roskam, I. (2018a). Consequences of parental burnout: its specific effect on child neglect and violence. *Child Abuse and Neglect*, 80, 134–155. <https://doi.org/10.1016/j.chiabu.2018.03.025>
- Misura, A. K., and H. Memisevic. 2017. "Quality Of Life Of Parents Of Children With Intellectual Disabilities In Croatia." *Journal of Educational and Social Research* 7 (2): 43–48. doi:10.5901/ jesr. 2017.v7n2p43. Doi:10.5901/jesr. 2017.v7n2p43
- Moghal, F., & Khanam, S. J. (2015). Development of ICP Subjective Well-Being Scale (SWBS). *Pakistan Journal of Clinical Psychology*, 14(2). Retrieved from <https://www.pjcpku.com/index.php/pjcp/article/view/68>

- Nam, S. J., & Park, E. Y. (2017). Relationship between caregiving burden and depression in caregivers of individuals with intellectual disabilities in Korea. *Journal of Mental Health, 26*(1), 50-56. <https://doi.org/10.1080/09638237.2016.1276538>
- Ochoa, S. G. (2023). *Quality of Life Among Caregivers of Individuals With 22q11. 2 Deletion Syndrome and Intellectual Disability* (Doctoral dissertation, The University of Texas Rio Grande Valley). doi: 10.1177/0192513X15572368.
- Panicker, A. S., & Ramesh, S. (2019). Psychological status and coping styles of caregivers of individuals with intellectual disability and psychiatric illness. *Journal of Applied Research in Intellectual Disabilities, 32*(1), 1-14. <https://doi.org/10.1111/jar.12496>
- Parchomiuk, M. (2022). Work-family balance and satisfaction with roles in parents of disabled children. *Community, Work & Family, 25*(3), 353-373. <https://doi.org/10.1080/13668803.2020.1764499>
- Patton, K. A., Ware, R., McPherson, L., Emerson, E., & Lennox, N. (2018). Parent-related stress of male and female carers of adolescents with intellectual disabilities and carers of children within the general population: A cross-sectional comparison. *Journal of Applied Research in Intellectual Disabilities, 31*(1), 51-61. <https://doi.org/10.1111/jar.12292>
- Pérez-Cruzado, D. 2019. "Changes on Quality of Life, Self-efficacy and Social Support for Activities and Physical Fitness in People with Intellectual Disabilities through Multimodal Intervention." *European Journal of Special Needs Education 31* (4): 553–564. doi:10.1080/08856257.2016.1187786.
- Pérez-Cruzado, D., and A. I. Cuesta-Vargas. 2016. "Changes on Quality of Life, Self-efficacy and Social Support for Activities and Physical Fitness in People with Intellectual Disabilities through Multimodal Intervention." *European Journal of Special Needs Education 31* (4): 553–564. doi:10.1080/08856257.2016.1187876.
- Perry, B., Potter, S., & Carpenter, L. (2017). Compassion fatigue and satisfaction: A cross-sectional survey among US healthcare workers. *Nursing & Health Sciences, 19*(2), 180-187. <https://doi.org/10.1111/nhs.12068>
- Perry, B., Potter, S., & Carpenter, L. (2021). Compassion fatigue and satisfaction: A cross-sectional survey among US healthcare workers. *Nursing & Health Sciences, 19*(2), 180-187. <https://doi.org/10.1111/nhs.12068>
- Pryce L, Tweed A, Hilton A, et al. (2017) Tolerating uncertainty: perceptions of the future for ageing parent carers and their adult children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities 30*(1): 84–96. <https://doi.org/10.1111/jar.12221>
- Roskam, I., Brianda, M. E., & Mikolajczak, M. (2018). A step forward in the conceptualization and measurement of parental burnout: the Parental Burnout Assessment (PBA). *Frontiers in Psychology, 9*, 758 <https://doi.org/10.3389/fpsyg.2018.00758>
- Ryan, C., & Quinlan, E. (2018). Whoever shouts the loudest: Listening to parents of children with disabilities. *Journal of Applied Research in Intellectual Disabilities, 31*, 203-214. <https://doi.org/10.1111/jar.12354>
- Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PloS one, 14*(7), e0219888. doi: 10.1371/journal.pone.0219888.
- Seltzer, M. M., Floyd, F., Song, J., Greenberg, J., & Hong, J. (2020). Midlife and aging parents of adults with intellectual and developmental disabilities: Impacts of lifelong parenting. *American journal on intellectual and developmental disabilities, 116*(6), 479-499. <https://doi.org/10.1352/1944-7558-116.6.479>

- Shahzad, S., & Ali, A. (2021). Burnout among caregivers of children with special needs: A study from Pakistan. *Journal of Child and Family Studies*, 30(7), 1846-1855. doi: 10.1016/j.jpedn.2018.12.007
- Shenaar-Golan, V. (2016). The subjective well-being of parents of children with developmental disabilities: The role of hope as predictor and fosterer of well-being. *Journal of Social Work in Disability & Rehabilitation*, 15(2), 77-95. <https://doi.org/10.1080/1536710X.2016.1162119>
- Singal, N. (2016). Schooling children with disabilities: Parental perceptions and experiences. *International Journal of Educational Development*, 50, 33-40. <https://doi.org/10.1016/j.ijedudev.2016.05.010>
- Singh, N. N., Lancioni, G. E., Chan, J., McPherson, C. L., & Jackman, M. M. (2020). Mindfulness-based positive behavior support. In *Handbook of Mindfulness-Based Programmes* (pp. 42-52). Routledge. <https://doi.org/9781315265438>
- Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., & Almeida, D. M. (2021). Daily stressors and coping strategies among mothers of adolescents and adults with autism spectrum disorder and intellectual disability. *Journal of Autism and Developmental Disorders*, 51(6), 1862-1874. <http://dx.doi.org/10.2139/ssrn.4832647>
- Stamm, B. H. (2005). Professional quality of life scale. *Psychological Trauma: Theory, Research, Practice, and Policy*. <https://doi.org/10.1037/t05192-000>
- Staunton, E., Kehoe, C., & Sharkey, L. (2023). Families under pressure: Stress and quality of life in parents of children with an intellectual disability. *Irish journal of psychological medicine*, 40(2), 192-199. doi:10.1017/ipm.2020.4
- Syed, I. H., Awan, W. A., & Syeda, U. B. (2020). Caregiver burden among parents of hearing impaired and intellectually disabled children in Pakistan. *Iranian Journal of Public Health*, 49(2), 249. doi: 10.5216/ree. v20.53190
- Szczygieł, D., Sekulowicz, M., Kwiatkowski, P., Roskam, I., & Mikolajczak, M. (2020). Validation of the Polish version of the Parental Burnout Assessment (PBA). *New Directions for Child and adolescent development*, 2020(174), 137-158. <https://doi.org/10.1002/cad.20385>
- Van keer, I., & Maes, B. (2018). Contextual factors influencing the developmental characteristics of young children with severe to profound intellectual disability: A critical review. *Journal of Intellectual & Developmental Disability*, 43(2), 183-201. <https://doi.org/10.3109/13668250.2016.1252458>
- Wang, P., Michaels, C. A., & Day, M. S. (2011). Stresses and coping strategies of Chinese families with children with autism and other developmental disabilities. *Journal of autism and developmental disorders*, 41, 783-795. <https://doi.org/10.1177/10883576211012599>
- Werner, S., & Shulman, C. (2019). Subjective well-being among family caregivers of individuals with developmental disabilities: The role of affiliate stigma and psychosocial moderating variables. *Research in developmental disabilities*, 34(11), 4103-4114. <https://doi.org/10.1016/j.ridd.2013.08.029>
- Williams, V., & Porter, S. (2017). The meaning of 'choice and control' for people with intellectual disabilities who are planning their social care and support. *Journal of Applied Research in Intellectual Disabilities*, 30, 97-108. <https://doi.org/10.1111/jar.12222>
- Yildiz, G., & Cavkaytar, A. (2020). Effectiveness of the parent training program for supporting the preparation of individuals with intellectual disability for adulthood on mothers'

- quality of life perceptions. *Education and Training in Autism and Developmental Disabilities*, 55(2), 201-214. <https://www.jstor.org/stable/27077911>
- Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., Danielson, M. L., Bitsko, R. H., ... & Boyle, C. A. (2019). Prevalence and trends of developmental disabilities among children in the United States: 2009–2017. *Pediatrics*, 144(4). <https://doi.org/10.1542/peds.2019-0811>
- Zuna, N., Summers, J. A., Turnbull, A. P., Hu, X., & Xu, S. (2011). Theorizing about family quality of life. *Enhancing the quality of life of people with intellectual disabilities: From theory to practice*, 241-278. https://doi.org/10.1007/978-90-481-9650-0_