Caregiver's Burden and Life Satisfaction in Caring for Disabled Children in Selangor

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ABSTRACT

Caregiving for children with disabilities (CWDs) can be very challenging for the children's family members, especially their caregivers and may affect their life satisfaction. This study explores the association between caregiver burden and life satisfaction among caregivers of children with disabilities. A descriptive cross-sectional design was utilized, focusing on caregivers from selected rehabilitation centers in Selangor. Data was collected using the validated instruments, ensuring comprehensive and reliable measures of burden and life satisfaction. Majority of respondents were aged 31-35, with a mean age of 35.75 ± 5.31 years. The children averaged 7.50 ± 3.09 years old. Most caregivers experienced a mild burden (53.3%), and 31.9% were slightly dissatisfied with their lives. The Zarit Burden Interview revealed the highest mean score in emotional well-being (11.07 ± 4.88) and the lowest in finances (1.96 ± 0.89). A Pearson correlation coefficient parametric test showed a strong, significant negative correlation between burden and life satisfaction ($r= -0.699$, $p< 0.001$), which indicates as the burden increases, life satisfaction decreases. Most caregivers experienced mild burden and slight dissatisfaction with their lives. Therefore, interventions such as policy development, financial support, and nursing assistance are needed to alleviate caregiver burden and enhance their quality of life.

Keywords—Burden, Caregiver, Life satisfaction, Disabled children

INTRODUCTION

Caring for children with disabilities (CWDs) presents significant challenges for their families, particularly caregivers, who often face social isolation due to community stigma. This stigma can result in discrimination against both the disabled child and their family (Hassan et al., 2021). Providing care for a child with disabilities presents considerable challenges that often lead to a caregiver burden, a multidimensional response encompassing emotional, physical, social, and financial strain. Numerous studies have shown that parents, particularly mothers of children with disabilities such as down syndrome, autism, or cerebral palsy, report higher levels of stress and reduced life satisfaction compared to parents of typically developing children (Fucà, et al., 2022; Rutter et al., 2024). Caregiver burden is shaped by various factors such as the severity of the child's condition, limited social support, financial strain, and the caregiver's ability to cope. Elevated burden levels are frequently linked to depression, anxiety, and social isolation.

Caregivers also incur substantial costs to meet their children's needs. A study by Ismail et al. (2022) on the economic burden for caregivers of children with cerebral palsy (CP) in Malaysia reported an estimated annual median cost of RM52,540.00 in 2020. These expenses, which include indirect, developmental, direct healthcare, and non-healthcare costs, can be particularly burdensome for low-income families.

On the other hand life satisfaction represents the caregiver's overall evaluation of their well-being and quality of life. Research indicates that caregivers with strong social support networks, access to healthcare resources, and adaptive coping mechanisms report better life satisfaction (Wang et al., 2022). Importantly, perceived meaning in caregiving and family cohesion also contribute positively to caregivers' life satisfaction.

Additionally, caregivers experience both physical and psychological stress while managing their child's behavioral and social challenges, such as aggression and temper tantrums commonly seen in children with autism spectrum disorder (ASD) as well as anxiety about their child's future. These stressors can lead to health problems like high blood pressure and depression (Wahab & Ramli, 2022). The overwhelming demands can diminish caregivers' life satisfaction and potentially result in neglect or abuse of the disabled child (Guan et al., 2021). Despite these challenges, some caregivers maintain a high level of life satisfaction.

The highest number of registered disabled persons in Malaysia (104,909 people, Malaysian Department of Social Welfare, 2023). Few studies have addressed these aspects in Malaysia, with most focusing on quality of life or economic burden in specific regions. This study aims to address that gap by exploring the current conditions and the correlation between caregiver burden and life satisfaction. The literature highlights a reciprocal relationship: increased burden can reduce life satisfaction, while improved psychological support and effective interventions can mitigate burden and improve well-being. Hence, understanding both concepts is essential in developing effective strategies to support caregivers of children with disabilities.

METHODOLOGY

This study utilized a quantitative, cross-sectional research design and was conducted at selected rehabilitation centers located in Selangor. The study targeted caregivers of disabled children aged 1 to 18, totalling 206 individuals.

The sample size was determined using the Raosoft calculator, with parameters set at a 5% margin of error and a 95% confidence level. The estimated required sample size was 135 from a total population of 206. The inclusion criteria for the respondents were caregivers and disabled children living together, having an email account, caregivers who understand English or Malay, and children diagnosed by a specialist. Exclusion criteria were lack of internet access and children over 18 years old.

Ethical approval was obtained from the UiTM Research Ethics Committee, FERC/FSK/MR/2023/00214 (Date: 8 November 2023) before the commencement of the study. Permission to conduct research involving caregivers of disabled children was obtained from the directors of the selected centers. Respondents were given a consent form, ensuring confidentiality and specifying that their information would be used solely for research purposes, as stated in the first section of the Google Form questionnaire.

Data collection was conducted over a three-month period, from November 2023 to February 2024, using a convenience sampling method. The Google Form survey link was provided to the directors of the selected centers, who then distributed it to willing caregivers via WhatsApp.

D. Instrumentations

For the demographic data, this section consists of 10 questions regarding the caregiver and children's characteristics: the caregiver's age, relationship with the disabled child, education level, marital status, occupation, number of disabled children, children's diagnoses, other diagnoses, children's ages, and ages of other children.

The burden level was assessed with the Zarit Burden Interview (ZBI-22). This section consisted of 22 items developed by Zarit et al. (1980). It consisted of five subscales: burden in the relationship, emotional well-being, social and family life, finances, and loss of control over one's life. The questionnaire uses a 5-point Likert scale to score the items, with 0 indicating never to 4 indicating nearly always. A total score of 0–20 signifies little to no burden, 21–40 denotes mild to moderate burden, 41–60 reflects moderate to severe burden, and 61–88 indicates a severe level of burden. The tool demonstrates high levels of reliability and validity.

Satisfaction With Life Scale (SWLS) used to measure a person's level of life satisfaction, consisted of five items (Diener et al., 1985). The questionnaire uses a 7-point Likert scale for scoring with scale 1 indicating very strongly disagree to scale 7 indicating very strongly agree. The SWLS scores range from 5 to 35. A score of 5 - 9 indicates extreme dissatisfaction, 10 - 14 reflects dissatisfaction, 15 - 19 suggests slight dissatisfaction, 20 is viewed as neutral, 21 - 25 indicates slight satisfaction, 26 - 30 shows satisfaction, and 31 - 35 represents extreme satisfaction. The tool was validated and reliable.

A pilot study was done with 30 samples of caregivers from one of the selected rehabilitation centers in Selangor before the actual study was conducted. Reliability tests showed excellent Cronbach's alpha values for both ZBI and SWLS, which were 0.95 and 0.83 respectively. Meanwhile for the ZBI’s domains demonstrated excellent values of Cronbach’s alpha which were 0.77, 0.86, 0.91, and 0.82 respectively, confirming the validity and reliability of the questionnaires and their domains.

Data analysis was performed using IBM SPSS Statistics Version 28. Both descriptive and inferential statistics (Pearson correlation) were applied. A p-value below 0.05 was considered statistically significant for rejecting the null hypothesis.

RESULTS

Distribution of Sociodemographic Data Among Caregivers in Selangor

A total of 135 respondents gave consent and participated in the research study. The data revealed that the average age of respondents was 31-35 years, with a mean of 35.75 ± 5.31 years. However, a significant portion of caregivers were between the ages of 36-40 years, (n= 50, 37.0%), with mothers making up the majority of caregivers, (n= 82, 60.7%). Most caregivers possessed tertiary education (n= 110, 81.5%), were married, (n= 119, 88.1%), and a large proportion were employed, (n= 99, 73.3%). A notable majority of the families had only one disabled child, (n= 133, 98.5%). Among the children, autism spectrum disorder (ASD) was the most prevalent diagnosis, (n= 53, 39.3%), followed by Down Syndrome, (n= 36, 26.7%) and Cerebral Palsy, (n= 19, 14.1%). Most children fell within the 6-10 age range, (n= 78, 57.8%), with a mean of 7.50 ± 3.09 years. Table 1 shows the sociodemographic data for caregivers, and Table 2 shows the sociodemographic data for children.

Table 1: Descriptive Data for Sociodemographic Data of Caregiver (N= 135)

Variables	**Frequency (n)**	**Percentage (%)**
Caregiver’s age (Mean= 35.75; SD= 5.31)		
Relationship		
Mother	82	60.7
Father	53	39.3
Education level		
Primary	2	1.5
Secondary	23	17.0
Tertiary	110	81.5
Marital status		
Married	119	88.1
Divorced/ single parent	16	11.9
Occupation		
Employed	99	73.3
Unemployed	36	26.7
Number of disabled children		

One child	133	98.5
Two children	2	1.5

Table 2: Descriptive Data for Sociodemographic Data of Children (N= 135)

Variables	Frequency (n)	Percentage (%)
Children diagnosis		
ADHD	7	5.2
ASD	53	39.3
CP	19	14.1
Development coordination syndrome	1	0.7
Down syndrome	36	26.7
Dyslexia	12	8.9
GDD	6	4.4
Rauch Steindl	1	0.7
Other children diagnosis		
ADHD	1	0.7
Down syndrome	1	0.7
Children age (Mean= 7.50; SD= 3.09)		
Other children age (Mean=6.5, SD=2.12)		

Note: ADHD= Attention Deficit Hyperactivity Disorder, ASD= Autism Spectrum Disorder, CP= Cerebral Palsy, GDD= Global Development Delay

Level of Burden in Caregiver Caring for Disabled Children in Selangor

The majority of caregivers experienced a mild burden, (n= 72, (.3%). This was followed by those experiencing a moderate burden, (n= 43, 31.9%), little to no burden, (n= 11, 8.1%), and severe burden, (n= 9, 6.7%).

Alternatively, the ZBI includes five domains, and these domains are composed of six, seven, four, one, and four items, respectively. The mean total ZBI score was 37.68 ± 14.07 (min = 10.00, max = 69.00), indicating a mild to moderate level of burden on average. The highest mean score among the ZBI domains was for emotional well-being (11.07 ± 4.88), followed by burden in relationships (10.98 ± 4.16). This was followed by loss of control over one's life (7.03 ± 2.16), social and family life (6.64 ± 3.73), and finally, finances (1.96 ± 0.89).

Level of Life Satisfaction in Caregiver Caring for Disabled Children in Selangor.

The majority of caregivers were slightly dissatisfied, (n= 43, 31.9%), followed by slightly satisfied, (n= 38, 28.1%), satisfied, (n= 20, 14.8%), dissatisfied, (n= 16, 11.9%), neutral, (n= 14, 10.4%), and extremely satisfied, (n= 4, 3.0%).

Alternatively, the mean of total score SWLS, 20.68 ± 5.21 (min= 10.00, max= 35.00), reflects neutral life satisfaction on average, with item Q2 "The conditions of my life are excellent," having the highest mean satisfaction score (4.67 ± 1.18) and item Q5 "If I could live my life over, I would change almost nothing," having the lowest (2.89 ± 1.43).

The Relationship Between Level of Burden and Level of Life Satisfaction in Caregiver Caring for Disabled Children in Selangor.

Table 3 shows the correlation between caregiver burden and life satisfaction, assessed using the Zarit Burden Interview (ZBI) and the Satisfaction with Life Scale (SWLS). The results showed a significant negative correlation across all areas, indicating that higher levels of burden were associated with lower life satisfaction. Specifically, the total ZBI score strongly correlated negatively with life satisfaction (r= -0.699, p< 0.001). Burden in relationships (r= -0.571, p< 0.001), emotional well-being (r= -0.654, p< 0.001), social and family life (r= -0.714, p< 0.001), and loss of control over one's life (r= -0.630, p< 0.001) all showed significant negative correlations. Even the burden related to finances, while weaker, was significant (r= -0.271, p= 0.001). These findings underscored the substantial impact of caregiver burden on overall life satisfaction. Therefore, the null hypothesis was rejected, confirming a significant relationship between caregiver burden and life satisfaction among caregivers of disabled children.

Table 3: The Correlation Between Level of Burden and Level of Life Satisfaction

ZBI	SWLS	p-value
Total Score ZBI	-0.699	<0.001*
Burden in Relationship	-0.571	<0.001*
Emotional Well-Being	-0.654	<0.001*
Social and Family Life	-0.714	<0.001*
Loss of Control Over One's Life	-0.630	<0.001*
Finances	-0.271	0.001*

DISCUSSION

Level of Burden in Caregiver Caring for Disabled Children in Selangor.

The burden level experienced by caregivers of disabled children has a significant effect on their well-being and quality of life. In this study, the mean score for caregiver burden indicated a mild to moderate burden, with most respondents experiencing mild burden, followed by moderate, little to no burden, and severe burden. This contrasts with Narayan and T.M (2023), where most caregivers experienced severe burden, but aligns with Shanbhag and Arasu (2021), Muñoz-Marrón et al. (2013), and Van Niekerk et al. (2023), who reported similar mean scores indicating mild to moderate burden. Notably, all studies used the 22-item ZBI, except Van Niekerk et al. (2023), who used a modified 12-item ZBI.

In this study, the highest mean for the ZBI domains was in emotional well-being, followed by burden in relationships, loss of control over life, social and family life, and finances. This differs from Ghazawy et al. (2020), using the Caregiver Burden Inventory (CBI), where emotional burden had the lowest mean score and time-dependent burden the highest. Pruthi (2021) used the Family Burden Interview Schedule and found the highest means in disruption of family leisure, mental health of family members, and financial burden. Despite different questionnaires, the domains measured were similar to those in the ZBI.

Level of Life Satisfaction in Caregiver Caring for Disabled Children in Selangor.

The level of life satisfaction among caregivers of disabled children is crucial for assessing their quality of life. In this study, the mean score indicated a neutral level of life satisfaction. Most caregivers were slightly dissatisfied, followed by slightly satisfied, satisfied, dissatisfied, neutral, and extremely satisfied. These findings contrast with Sulaimani et al. (2023), who used the RAND 36-Item Short Form Health Survey (SF-

36) and found a moderate level of quality of life, and Alias et al. (2019), who reported slight satisfaction using the SWLS tool, similar to this study. However, Majumdar and Jain (2020), using the WHOQoL-BREF questionnaire, found lower life satisfaction with a low mean score. Despite differences, previous studies indicated good overall life satisfaction among respondents.

Relationship Between Level of Burden and Level of Life Satisfaction in Caregiver Caring for Disabled Children in Selangor.

The relationship between caregiver burden and life satisfaction among those caring for disabled children is crucial for understanding the impact of caregiving responsibilities on wellbeing. This study identified a strong inverse relationship between caregiver burden and life satisfaction, indicating that increased burden leads to lower life satisfaction.

The ZBI dimension related to social and family life showed the strongest negative correlation with life satisfaction, suggesting that difficulties in social connections and family dynamics significantly decrease life satisfaction. Emotional well-being also showed a strong negative correlation, as caregivers often face significant emotional strain and psychological stress, leading to depression, anxiety, and emotional exhaustion. The domain of loss of control over one's life was another critical factor, as caregivers often feel overwhelmed and frustrated by their responsibilities, reducing their overall well-being and life satisfaction.

Caregiver burden and life satisfaction are deeply influenced by cultural norms, expectations, and support systems. In collectivist cultures, such as in many Asian societies including Malaysia, caregiving responsibilities often fall on the mother and are viewed as a family obligation rather than a choice. This cultural expectation may lead caregivers to internalize stress, suppress emotional expression, and avoid seeking external help ultimately increasing their burden. Studies have shown that when caregivers perceive limited support, both emotionally and practically, the accumulated burden significantly reduces their life satisfaction (Bongelli et al., 2024). On the other hand, caregivers in cultures that emphasize communal support or offer structured social services report a relatively lower burden and better quality of life (Wang et al., 2022). These differences highlight the importance of culturally sensitive approaches in understanding caregiver experiences. These findings align with prior research. Muhamad et al. (2022) identified a strong negative correlation between parental stress and life satisfaction, Mervenur and Dilek (2023) observed a weak negative correlation between family quality of life and fatigue, and Khan et al. (2021) reported a moderate negative correlation between caregiver burden and life satisfaction. Despite using different tools, these studies similarly observed that increased stress and burden lead to decreased life satisfaction, supporting the results of this study.

Limitation

This study had several notable limitations. One significant limitation was the potential for respondents to be dishonest, particularly with sensitive questions, such as question 18 in the Zarit Burden Interview (ZBI), which asked if they wished to leave the care of their child to someone else. This social desirability bias could lead to underreporting of burden and dissatisfaction, affecting data accuracy.

This study involved a relatively small sample and was confined to selected rehabilitation centers in Selangor, limiting the generalizability of the findings to the wider caregiver population. Nevertheless, the study’s strengths include a high response rate and the utilization of validated instruments. Future research should use larger, more diverse samples and qualitative designs for a deeper understanding of caregivers' experiences. This study highlights the importance of comprehensive support and targeted interventions to enhance caregivers' well-being and overall life satisfaction.

CONCLUSION

This study provides valuable insights into the burden and life satisfaction of caregivers of disabled children, revealing a significant negative correlation between these factors. The strongest impact was on social and family life, highlighting how increased caregiving responsibilities reduce life satisfaction. Recommendations include developing policies, providing financial assistance, and offering nursing support to alleviate caregiver burden and enhance their quality of life.

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Conflict Of Interest

None

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