

Factors Influencing the Quality of Life of Family Caregivers of Children with Neurodevelopmental Disorders (NDDs)

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RESEARCH ARTICLE INFORMATION	ABSTRACT
<p>Received: February 04, 2025 Reviewed: May 5, 2025 Accepted: June 17, 2025 Published: June 30, 2025</p> <p> Copyright © 2025 by the Author(s). This open-access article is distributed under the Creative Commons Attribution 4.0 International License.</p>	<p>Caring for children with Neurodevelopmental Disorders (NDDs), specifically Autism Spectrum Disorder (ASD) and Attention-Deficit/Hyperactivity Disorder (ADHD), presents unique challenges that impact the quality of life (QoL) of family caregivers. Thus, this study aimed to assess the quality of life (QoL) and associated factors among family caregivers (FGCs) of children with NDDs in Isabela. Purposive sampling was used to obtain 111 respondents. QoL was measured using the Adult Caregiver Quality of Life Questionnaire (AC-QoL). The data gathered was analyzed using SPSS version 22. Inferential analysis indicated that caregivers generally experienced a mid-range quality of life (64.86%), with a notable minority reporting high QoL (20.72%). While high scores were observed in personal growth and career satisfaction, reduced QoL was found in the dimensions of caring choice, money matters, caring stress, and support for caring. The study also confirmed statistically significant differences in QoL based on age, occupation, length of caregiving, and diagnosis of the child. These findings underscore the complex interplay of factors influencing caregiver well-being and highlight the need for tailored interventions to enhance caregiver support programs and ultimately improve the quality of life for both caregivers and their children.</p>

Keywords: *Neurodevelopmental Disorders, Family Caregivers, Autism Spectrum Disorder, ADHD, Quality of Life*

Introduction

Caring for a child with a neurodevelopmental disorder (NDD) is a complex and demanding journey that can significantly impact the quality of life (QoL) of family caregivers. NDDs, encompassing a wide range of conditions such as autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD), are characterized by developmental deficits that affect personal, social, academic, or occupational functioning (Carona et al., 2014; Haque et al., 2021; Lach et al., 2009). The chronic stress, emotional exhaustion, and physical fatigue associated with caring for a child with an NDD can have a profound negative impact on the caregiver's mental and physical health (Mori et al., 2017), aligning with the United Nations Sustainable Development Goals (SDGs) of promoting good health and well-being (SDG 3) and reducing inequalities (SDG 10).

The World Health Organization (WHO) reports that approximately 15% of the world's population, or about 96 million people, have NDDs. These include children and adolescents, aged 0-17 years. Across countries, an upward trend in the prevalence of autism has been documented and well-researched. The issue of disability is often connected with QoL research, particularly in relation to the family or parents of a child with disability (Letovancová & Slaná, 2022). This trend then calls for deeper and more intensive exploration of the underlying factors surrounding autism, especially towards providing support and care for families and caregivers in low- and middle-income countries.

Significant challenges and stressors are often uniquely faced by caregivers in emerging countries, such as the Philippines (Roepert et al., 2022). The prevalence of NDDs in the Philippines is a pressing public health concern, with millions of Filipino children estimated to be living with disabilities (National Council on Disability Affairs, 2024). According to the Autism Society of the Philippines, approximately 1.2 million Filipinos, constituting 1 out of 100 individuals, have clinically diagnosed autism. Despite this substantial prevalence, research exploring the unique experiences and challenges faced by caregivers of children with NDDs in the Philippines remains limited.

Research findings highlight the significant impact of the child's disability on the entire family, suggesting that in the Philippine context, the family, not just the individual, may be considered the unit of disability experience (Lasco et al., 2022). They also emphasized that Filipino parents experience the disability alongside their children, facing shared challenges such as stigma, discrimination, and financial burden. Support groups are identified as an invaluable source of assistance for parents (Bailey, 2024; Gomez, 2013).

This research gap underscores the need for further investigation into the specific cultural, social, and economic factors that influence caregiver well-being in the Philippine context. While the research agenda on caregiver QoL for children with disabilities in the Philippines is active, studies thus far highlight that it is still an area with significant gaps. Current research is contributing by providing initial quantitative data on QoL levels and influencing demographic factors in specific regions, particularly in rural areas like Isabela province. This scarcity of resources, coupled with limited public awareness and stigma surrounding NDDs, amplifies the challenges faced by caregivers and further diminishes their QoL.

Impact of Caregiving

The relentless demands of caregiving can strain relationships within the family. The psychological effects of parental stress extend beyond immediate family dynamics. Wolf et al. (1989) reported that parents of autistic children often face isolation from family and friends, which is a significant life stressor. Cheng et al. (2018) strengthened this claim by demonstrating how a lack of social support contributes to negative outcomes such as depression, social isolation, and spousal relationship problems.

The link between mental health and QoL among caregivers of children with NDDs has been well-studied and long-established in research. Caregivers often experience elevated levels of stress, anxiety, depression, and sleep deprivation (Roeper et al., 2022), as well as social isolation (Cheng et al., 2018) and financial strain (Salomone et al., 2021) due to the demanding nature of caregiving responsibilities. These factors can significantly impair caregivers' mental health, leading to a reduced QoL and hindering their ability to provide optimal care, maintain healthy relationships, and participate fully in social and occupational activities.

On the other hand, a study conducted by Beighton and Wills (2017) explored the positive aspect of parenting children with disabilities. Emerging themes included an increased sense of personal strength and confidence, changed priorities, greater appreciation of life, pleasure in the child's accomplishments, increased faith/spirituality, more meaningful relationships, and the positive effect that the child has on the wider community. Interpretive examination of the themes revealed that the positive aspects identified consist mostly of meaning-focused coping strategies. These enable parents to adapt successfully to the stressful experiences of raising their child and, therefore, could be amenable to meaning-focused therapeutic interventions for parents with newly diagnosed children or for those unable to identify any positive aspects of parenting their child.

The above-mentioned factors indicate that families with children with a disability are subject to an enormous burden, and this directly affects the quality of life of individual family members, especially parents. It is important to mention that the quality of life of parents of children with disability is interlinked with the quality of life of the disabled child and other family members (Kotzampopoulou, 2015; Parkes et al., 2011). Dervishaliaj (2013) stated that parental stress reciprocally affects the child with disability. The more dissatisfied the parents are, the more stress they feel, and consequently, they meet the child's needs to a lesser extent, lowering the quality of their child's life. This is why we consider it important to pay attention to the topic of life quality of a family of a child with disability, as well as to the factors affecting the quality of life. As a result, a better understanding of the quality of life and the factors affecting it can help to provide more direct assistance to the affected families.

Thus, this research aimed to assess the quality of life of family caregivers in Isabela. The main objective of this study was to determine the level of quality of life among family caregivers caring for children with Neurodevelopmental Disorders. Furthermore, it sought to know whether there were differences in the quality of life of the family caregivers based on their demographic profile. This study then aimed to address this critical gap by adding a significant foundation for developing a comprehensive and accessible psychoeducational training manual that equips caregivers with the knowledge, skills, and coping mechanisms necessary to effectively manage NDDs, navigate the complex healthcare and educational systems, and foster a supportive and inclusive environment for their children and families.

Methods

Research Design

This study employed a descriptive-comparative research design to determine the quality-of-life level among family caregivers when grouped according to their respective demographic profile.

Respondents

The main respondents of this research are informal or family caregivers of individuals with ASD and ADHD. The total number of family caregivers was obtained in various Public Special Education Centers and had undergone proper allocation of respondents through purposive sampling, considering the following criteria: (a) Respondents must be residents of Isabela; (b) They must be family members who are actively involved in delivering care or caregiving responsibilities for 3 years and above; and (c) Must be 21 years old and above.

As for the children with NDDs being cared for, the following inclusion criteria were followed: a) The child must be 17 years old and below; b) He must be clinically diagnosed or have undergone clinical or developmental assessment, indicating a severity level of moderate to severe. Only one caregiver per child with NDD will be permitted.

Research Instrument

A Survey questionnaire was utilized in this study, which comprises two parts: the first part ascertained the demographic profile of the respondents, and the second part measures the respondents' level of Quality of Life (QoL). A standardized questionnaire, namely the *Adult Caregiver Quality of Life Questionnaire* (AC-QoL) by Elwick et al., 2010. It is a 40-item self-report questionnaire that measures the quality of life of adult carers in eight separate domains (subscales): support for caring, caring choice, caring stress, money matters, personal growth, sense of value, carer satisfaction, and ability to care. All of the questions were assessed on a 4-point Likert scale, from "Never" to "Always". In terms of internal consistency reliability for the total 40-item scale, the AC-QoL was 0.94. Internal consistency reliability for the eight subscales ranged from 0.78 to 0.89, indicating high reliability.

Procedure

The researcher first sought approval to conduct the study at Isabela State University, Echague Campus. Upon approval, the researcher communicated with the two existing public SpEd Centers in order to know the total number of children enrolled under their Learners with Special Education Needs (LSEN) Program diagnosed with ASD and ADHD (Table 1), and to ask permission from the principal and teacher-in-charge regarding the conduct of the study.

Table 1. Number of Children Enrolled Under Learners with Special Education Needs (LSEN) Program Diagnosed with ASD and ADHD

SPED Center	ASD	ADHD	Total
Santiago North Central School	56	24	80
Cauayan South Central School	53	22	75

Once the information needed was gathered, the researcher asked for the assistance of the teachers in charge of the different LSEN classes for the dissemination of the research conducted, and to gather the names and contact information of interested respondents. Once the required number of respondents was reached, informed consent was distributed and discussed.

Upon their confirmation to participate, survey questionnaires were distributed and administered one by one. The distribution and collection of questionnaires took place from June to November 2024. Data obtained from the survey questionnaires were analyzed using the Statistical Package for the Social Sciences (SPSS) version 21.0. Descriptive Statistics, particularly frequency count and percentage, were used to describe the profile of the respondents according to their age, sex, education, income, occupation, relationship to a child with ASD and ADHD, and number of years being a family caregiver. The participants' level of Quality of Life (QoL) was determined through a scoring template (Appendix A), which was used in computing the scores of each participant.

Ethical Considerations

This research has been reviewed and approved by the Dean of the Isabela State University-Central Graduate School, ensuring adherence to ethical guidelines. All respondents were provided with written informed consent disclosing the purpose, procedures, risks, and benefits of the study. Their right to participate was also highlighted, including the right to withdraw at any time. Confidentiality and anonymity were strictly maintained through secure data storage and anonymization of individual data. The respondents were treated with respect and dignity throughout the research process and informed of their rights, including access to their data within confidentiality limits.

Results and Discussion

A total of 111 family caregivers were included in this study. Table 2 presents the demographic profile of the respondents, wherein the majority (64.86%) of the respondents are female caregivers. Most caregivers are middle-aged, with the largest group (36.94%) falling within the 25-35 age range. They tend to have a college education (68.47%) and come from lower-middle-income households (37.84%). These caregivers have typically been providing care for 4-6 years (46.85%), highlighting their long-term commitment to this role. This data is consistent with previous research stating that mothers and female caregivers take more active roles in caregiving responsibilities to their children (Letovancová, 2022; Roeper et al., 2022). It also underscores the need for support systems that cater to the specific needs and challenges faced by this demographic (Cheng et al., 2018).

The data also reveals a diverse range of occupations among caregivers. Blue-collar workers (e.g., tricycle drivers, market vendors, etc.) make up 30.63% of the sample, followed by open-collar workers (online sellers, call center, and customer service representatives) with 22.52%, and white-collar workers (e.g., teachers, firemen, police officers) with 18.92%. A significant proportion (27.93%) are full-time carers. This diversity emphasizes the widespread impact of neurodevelopmental disorders across various socioeconomic backgrounds. While most caregivers are parents (66.67%), a notable number are siblings (15.32%) and extended family members (18.02%), indicating that the responsibility of care often extends beyond the immediate family.

Moreover, the respondents are seen to have at least a high school (22.52%) to college (68.47%) educational background, of which the majority reached and graduated from college (68.47%). This raises awareness about whether the manual's content and delivery should be tailored to different education levels to ensure accessibility and effectiveness for all caregivers. Additionally, the financial challenges faced by many caregivers, with 27.03% reporting "low" income and 18.92% reporting "poor" income, highlight the importance of considering affordability and accessibility when developing and implementing support programs.

Table 2. Demographic Profile of the Respondents

Demographics	Number of Respondents	Percentage
Sex		
Female	72	64.86
Male	39	35.14
Age		
21-31	22	19.82
32-41	41	36.94
42-51	18	16.22
52-61	24	21.62
62 and over	6	5.41
Education		
Elementary	4	3.60
High School	25	22.52
College	76	68.47
Graduate Studies	6	5.41
Income		
Poor	21	18.92
Low	42	37.84
Lower-Middle	30	27.03
Middle	13	11.71
Upper-Middle	4	3.60
Rich	1	0.90
Occupation		
Blue Collar	34	30.63
White Collar	21	18.92
Open Collar	25	22.52
Full-time Carer	31	27.93
Relationship		
Parent	74	66.67
Sibling	17	15.32
Extended Family	20	18.02
Years of Caregiving		
1-3	17	15.32
4-6	52	46.85
7-9	31	27.93
10 years & up	11	9.91

Subsequently, it shows that there are more male (57.66%) than female (42.34%) children, mostly between the ages of 5 to 9 years old (63.96%). The majority of these children are diagnosed with Autism Spectrum Disorder (ASD) with varying levels, i.e., ASD Level 1 (28.83%), ASD Level 2 (24.32%), and ASD Level 3 (18.02%). On the other hand, a significant number of children are also diagnosed with Attention Deficit/Hyperactivity Disorder (ADHD) with mild (15.36%), moderate (10.81%), and severe (2.70%) severity. It is important to note that these children are all enrolled under the Special Education Program of Santiago North Central School (62.16%) and Cauayan South Central School (36.93%).

Table 3. Demographic Profile of the Child

Demographics	Number of Respondents	Percentage
Sex		
Female	47	42.34
Male	64	57.66
Age		
5-9	71	63.96
10-13	26	23.42
14-17	14	12.61
Diagnosis		
ASD Level 1	32	28.83
ASD Level 2	27	24.32
ASD Level 3	20	18.02
ADHD (Mild)	17	15.36
ADHD (Moderate)	12	10.81
ADHD (Severe)	3	2.70
SPED School Enrolled at		
Cauayan South Central School	41	36.93
Santiago North Central School	69	62.16

Subscale scores for the AC-QoL survey present the data gathered, indicating that caregivers generally experience a moderate level of quality of life, as evidenced by the mid-range scores on six out of the eight subscales of the Adult Carer Quality of Life (AC-QoL) scale. These subscales include Support for Caring ($M=10.84$), Caring Choice ($M=8.66$), Caring Stress ($M=9.12$), Money Matters ($M=8.57$), Sense of Value ($M=9.24$), and Ability to Care ($M=10.56$).

However, there are two notable exceptions: Personal Growth ($M=12.43$) and Career Satisfaction ($M=11.57$), both of which exhibit high scores. This suggests that caregivers derive a strong sense of personal development and satisfaction from their caregiving roles, despite the challenges they may face.

Table 3. Mean per QoL Subscale

Demographics	Weighted Mean	Descriptive Interpretation
1. Support for Caring	10.84	Mid-range QoL
2. Caring Choice	8.66	Mid-range QoL
3. Caring Stress	9.12	Mid-range QoL
4. Money Matters	8.57	Mid-range QoL
5. Personal Growth	12.43	High QoL
6. Sense of Value	9.24	Mid-range QoL
7. Ability to Care	10.56	Mid-range QoL
8. Carer Satisfaction	11.67	High QoL

Overall, QoL levels of the respondents are reported to be along the mid-range QoL level, indicating a balance of challenges and rewards; a significant minority (20.72%) experienced a high QoL, marked by personal growth and satisfaction. However, a concerning 14.41% of the respondents reported a low QoL, suggesting substantial difficulties and potential risks. These findings align with the subscale scores, where most fell within the mid-range, with Personal Growth and Career Satisfaction domains notably higher. This data underscores the need for a comprehensive psychoeducational training program tailored to caregiver needs.

Table 4. Quality of Life (QoL) Level

QoL Level	N	Percentage
Low QoL	16	14.41
Mid-range QoL	72	64.86
High QoL	23	20.72

Lastly, this research confirms the existence of statistically significant differences in the overall quality of life level with regard to respondents' sex ($F=0.433$, $p=0.238$), age ($F=0.728$, $p=0.043$), income ($F=7.369$, $p=0.113$), occupation ($F=0.621$, $p=0.027$), length of caregiving ($F=0.532$, $p=0.003$) and diagnosis of child ($F=0.421$, $p=0.031$).

Table 5. Differences in Quality of Life According to Demographic Profile

Demographical Factor	F	p-value
Sex	0.433	0.238
Age	0.728	0.043
Income	7.369	0.113
Occupation	0.621	0.027
Length of Caregiving	0.532	0.003
Diagnosis of the Child	0.421	0.031

The findings revealed that male parents reported the highest quality of life compared to their female counterparts. Hence, female caregivers are more likely to have a lower QoL level. On the other hand, caregivers aged 36-44 tend to have higher QoL

levels as compared to caregivers aged 24-35 years old, who exhibited the lowest QoL level. On the data for income and occupation, the data confirms previous research stating that caregivers in the poor-low-income bracket experience the lowest QoL as compared to middle-class family caregivers. Moreover, it shows that full-time caregivers exhibit much higher QoL than those working in both blue- and white-collar occupations. This contradicts insights from other resources suggesting that financial strain and needing to give up work negatively impact parents (Bailey, 2024; Gomez, 2013).

It is notable that the length of caregiving impacts QoL levels, wherein family caregivers with 1-3 years of caregiving experience tend to experience lower QoL levels than those who have more years of experience in taking care of the child. This is somewhat similar in the aspect of the diagnosis, wherein caregivers taking care of children with ASD Level 1 and ADHD experience lower levels of QoL than those taking care of children with ASD Level 2 and 3. Conversely, another study found no connection between the type of disability and QoL in their research, assuming that the very existence of a disability, regardless of its type, influences parental QoL (Letovancová, 2022).

According to Ones et al. (2005) and Glenn et al. (2008), the degree of stress of parents is not so much related to the level of functioning of the child, but rather to their access to resources and support. This view is shared by our research results. The area of social support has been shown to have a significant impact on the overall quality of life of a parent with a child with disability. Reduced emotional well-being was associated with insufficient emotional support (Bailey, 2022; Cheng et al., 2018; Dervishalia, 2013).

This was reflected in their answers related to the overall quality of life, which scored significantly higher. Higher satisfaction with social support could also be influenced by the fact that contact with the respondents was mediated by institutions providing support to families with children with disability, such as special-pedagogical counselling centers, early intervention centers, and social services guaranteeing the provision of early intervention, day care centers, as well as special schools. In view of the above findings, it is deemed essential that families with a child with disability be provided with care and support that enables them to operate at the optimal level and live a quality life comparable to families with a child without disability (Brown et al., 2006). Thus, appropriate and high-quality support from family, professionals, and services can reduce parents' stress levels and increase their emotional well-being (Parkes et al., 2011).

Conclusion and Future Works

This research aimed to assess the quality of life level of family caregivers in Isabela and further investigate the factors underlying their QoL Level. This study, then, confirmed the complex interplay of factors influencing the quality of life of FGCs of children with neurodevelopmental disorders. The primary finding indicated that while a majority of caregivers experienced a moderate overall QoL, a significant portion also derived substantial personal growth and satisfaction from their caregiving roles. However, persistent challenges, particularly in managing caring stress and financial concerns, were evident. This study underscored that caregiver QoL is not uniform; rather, it is significantly influenced by significant factors, including the caregiver's age, occupation, the duration of their caregiving journey, and the specific diagnosis of the child. These demographic and situational variables create a diverse exploration of

caregiving experiences, highlighting that a one-size-fits-all approach to support is insufficient.

The findings of this study align with existing literature on the challenges and rewards of caring for children with NDDs. The moderate to high QoL reported by caregivers echoes Beighton and Wills' (2017) research, which highlighted the positive aspects of parenting children with disabilities, such as personal growth and meaningful relationships. However, the study also confirms the presence of stressors, such as financial strain and the need for adequate support, as documented in previous research (Cheng et al., 2018; Mori et al., 2017; Salomone et al., 2021). The significant differences in QoL based on sex, age, income, occupation, and the child's diagnosis emphasize the need for personalized support systems.

The contribution of this study lies in its portrayal of caregivers. This research investigates QoL in a specific Philippine context, aiming to move beyond a traditional deficit model. By identifying both the burdens and the often-overlooked positive psychological outcomes, like personal growth, these findings offer new insights for researchers and practitioners. For researchers, this study provides a foundation for exploring the protective factors and resilience mechanisms that contribute to higher QoL despite caregiving demands. For practitioners, it emphasizes the need to develop interventions that not only alleviate stress but also acknowledge and foster the positive aspects of caregiving, thereby promoting a more holistic sense of well-being. Understanding this complex interplay is crucial for designing effective support systems that genuinely address the lived realities of these caregivers.

It is important to note that this study only focused on the public SPED Centers available in Santiago City and Cauayan City, Isabela. Future researchers may consider conducting a comparative study on families undergoing private intervention services and how they impact their overall QoL.

Ultimately, this study serves as a call to action: investing in the well-being of caregivers is an investment in the well-being of children with NDDs and the family unit as a whole. Based on these findings, it is strongly recommended that future research delves deeper into specific coping mechanisms and culturally sensitive support systems that demonstrably enhance caregiver QoL. The development and evaluation of comprehensive psychoeducational training programs tailored to the diverse needs of caregivers are crucial. These programs should focus on stress management, financial literacy, and building resilience. Additionally, healthcare providers and social service agencies should be equipped to provide personalized support, recognizing the multifaceted challenges faced by caregivers. Gallena and Bergantiños (2024) emphasized the crucial role of the Local Government Units (LGUs) in addressing and mobilizing action for future public health responses. By addressing these issues, we can empower caregivers, enhance their well-being, and ultimately improve the quality of life for both caregivers and their children.

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Conflict of Interest

The author declares that there are no conflicts of interest regarding the publication of this paper.

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