

Caregiver Burden and Well-being of Caregivers to Hospitalized Filipino Children with Neurological Conditions: A Cross-sectional Study

Lyra C. Ceblano, MD,^{1,2} Benilda C. Sanchez-Gan, MD^{1,3} and Patricia C. Orduña, MD^{1,4}

¹Division of Pediatric Neurology, Departments of Pediatrics and Neurosciences, Philippine General Hospital, University of the Philippines Manila, Manila, Philippines

²Department of Pediatrics, Eastern Visayas Medical Center, Tacloban, Leyte, Philippines

³Section of Child Neurology, Institute for Neurosciences, St. Luke's Medical Center, Quezon City, Philippines

⁴Department of Pediatrics, Manila Medical Center, Manila, Philippines

ABSTRACT

Background. Taking care of pediatric patients with neurological conditions in prolonged hospital stays can affect caregivers' health due to the demands of caregiving beyond daily parenting.

Objectives. The study aimed to determine the association between caregiver burden and well-being among caregivers of hospitalized Filipino children with neurological conditions, and the prevalence rate of caregiver burden, and assess the subjective perception of well-being of caregivers attending to these patients.

Methods. A cross-sectional study was conducted among 95 primary caregivers of pediatric patients with neurological conditions admitted to the Pediatric Neurology ward of the Philippine General Hospital from December 2024 to January 2025. Eligible participants were selected through purposive sampling. Data were collected using a structured questionnaire covering sociodemographic and clinical information, the Modified Caregiver Strain Index–Filipino (MCSI-F) to assess caregiver burden, and the World Health Organization–Five Well-being Index (WHO-5) to assess subjective well-being. Descriptive statistics, Pearson correlation, and univariable logistic regression were used for data analysis at a 0.05 level of significance.

Results. The mean age of participants was 35 years, with most being mothers (79%), female (87%), and unemployed (48%). The prevalence of caregiver burden was 59%, with 23% reporting severe strain. Impaired well-being was found in 92% of participants. Although caregivers with burden showed higher odds of impaired well-being (OR 4.91, 95% CI 0.93–25.76), the association was not statistically significant ($p = 0.060$). No caregiver or patient characteristic showed a significant relationship with burden or well-being.

Conclusion. High prevalence rates of caregiver burden and impaired well-being, among caregivers of hospitalized Filipino children with neurologic conditions at a single tertiary center, were seen. Interventions such as periodic psychosocial and caring support and development of family-centered care plans may be considered to help decrease the burden of care in caregivers among this population.

Keywords: caregiver, burden, well-being, pediatric neurology

Corresponding author: Lyra C. Ceblano, MD
Division of Pediatric Neurology
Departments of Pediatrics and Neurosciences
Philippine General Hospital
University of the Philippines Manila
Taft Avenue, Ermita, Manila 1000, Philippines
Email: laiceblano@yahoo.com
ORCID: <https://orcid.org/0009-0001-8942-1068>

INTRODUCTION

Neurological disorders are the foremost cause of disability and the second leading cause of death globally.¹ These neurological conditions are a major cause of hospitalization and care among children and young adults worldwide. The increasing number of deaths and disabilities caused by neurological disorders is recognized as a global public health challenge, with the greatest burden in low- and middle-income countries.¹ In 2019, the disability adjusted life-years (DALY) of neurological disorders reached 64.6 million in Southeast Asia and 85 million in the Western Pacific regions.² In the Philippines, however, there is limited data on the extent of pediatric patients with neurological conditions in the country.

Among the few hospitals providing neurological care in the Philippines, the Philippine General Hospital (PGH) – through its Department of Neurosciences, including sections of Pediatric Neurology, Adult Neurology, and Neurosurgery – is a tertiary care hospital catering to all neurological cases referred from across the country. In 2015, the annual inpatient admissions for the whole hospital reached 45,092, with 4,286, or 9.3%, admitted due to neurological cases. Of this, 58% were in-patient admissions under Charity Service, consistent with the hospital's mandate to serve the low- and middle- income families. By section, 55.2% of the 4,286 cases were in Adult Neurology, 26.6% in Neurosurgery, and 18.2% in Pediatric Neurology.³ The top causes of admissions were due to incidences of stroke, intracranial tumors, CNS infections, episodes of epilepsy, congenital malformations, and traumatic head injuries. In terms of outpatient care in the same year, epilepsy is the topmost reason for consult both for adult and pediatric cases. PGH recorded 5,028 neuro-related patient visits, with 40.92% among adults and 76.6% in children.³ For neurosurgery, there were 1,012 operations that year, with ventriculoperitoneal shunt insertion as the most common procedure, followed by intracranial tumor excision and aneurysm surgery.³

When it comes to admissions, patients rely on family and friends to support their ordeal. More so for children, who are legally under the care of adults in their lives. In the Philippines, any visit to a hospital, whether for outpatient or inpatient care, is often accompanied by family, relatives, or friends to actively complement professional care provided in hospitals and other medical settings. Hospitalization, regardless of whether planned /unplanned, single admission or recurring, is disruptive to family members and to caregivers. Several factors are associated with stress among caregivers and family, including type of admission, illness severity, and length of stay.⁴

As most chronic disabilities are characterized by mental or physical impairment, or both, the complex and specialized regimen required to manage children with neurological deficits, disabilities, or disorders may cast a burden on families to provide care beyond typical responsibilities and

support.^{5,6} Caregivers are faced with concerns about medical appointments, handling medication routines, financial woes, dealing with changes in their children's functions, and stigma from others. These challenges are characterized by different levels of stress, anxiety, depression, and social isolation that may be experienced by caregivers of children with special needs due to their medical conditions.⁷

Globally, studies have reported that caregivers of children with chronic neurological disorders experience high levels of stress, fatigue, and emotional exhaustion.^{6,8,9} However, findings on the predictors and outcomes of caregiver burden have been inconsistent. Some studies found that older caregivers experience greater burden due to declining health and fewer coping resources, while others reported no significant association with age.¹⁰⁻¹² Likewise, higher education and employment status have been linked to lower burden in some studies, yet others suggest that education increases caregivers' awareness of their children's prognosis, which can heighten psychological strain.^{13,14} These contradictions underscore the need for contextual, population-specific analyses.

Despite the increasing global recognition of caregiver strain, limited studies have explored the burden and well-being of caregivers in hospital-based pediatric neurological settings, particularly in low- and middle-income countries like the Philippines.

In pediatric neurology, most research has focused on outpatient or ambulatory cases such as epilepsy, while limited attention has been given to caregivers of hospitalized children with varied neurological diagnoses.¹⁴⁻¹⁶ Studies in Nepal and Egypt emphasized that socio-economic pressures and limited health literacy amplify caregiver stress, but such findings may not reflect the Filipino caregiving context, where extended family systems and shared caregiving roles influence outcomes.^{13,14} Moreover, evidence on the relationship between caregiver burden and well-being remains inconclusive: some report a strong negative correlation, while others found no significant link when controlling for social support and coping mechanisms.^{10,14,15,17,18}

Given these inconsistencies and the paucity of local data, this study aims to examine caregiver burden and well-being among caregivers of hospitalized Filipino children with neurological conditions – providing critical baseline data to inform psychosocial support strategies within pediatric tertiary care settings.

Review of Related Literature

In this study, the well-being of caregivers is given importance, or is considered as important as the patients' conditions themselves. The caregiver's quality of life (QoL) is measured against the pressures and emotional toll of caregiving while pursuing other life objectives.¹⁹ While there is no definitive standard to measure caregiver impact, similarly, long-term caregiving is associated with four overarching quality of life domains: (i) physical health, (ii) mental health, (iii) social function, and (iv) financial resources.¹⁹ For issues specific to

neurological care, caregivers are seen to carry the burden on (i) seizure/symptom worry, (ii) emotional well-being, (iii) energy/fatigue, (iv) future of the children, and (v) medication and cognitive effects of the patients.¹⁹

To date, studies in determining the quality of life among caregivers of children with neurologic conditions have been recorded specifically for epilepsies within mostly developed countries.^{8,20} Similar studies in Nepal and Egypt have provided insights into the cases of caregivers of epileptic children as well.^{13,14} In the Philippines, there is limited published data on caregiver burden among in-patient children, one conducted with caregivers of children with epilepsy, and another for caregivers of children with neurodevelopmental issues, both of which were conducted based on outpatient and ambulatory settings.^{15,16}

Factors affecting caregiver burden have also been investigated among caregivers of the adult population.^{10,21} However, in the pediatric population, studies are more limited. Caregiver characteristics such as sex, age, education, and employment status have been identified as predictors of caregiver burden.^{9,10,12,16} It was found that female and older caregivers were associated with higher burden.^{10,12} While caregivers with higher education, employed, and with higher income were negatively associated with the burden of care.^{13,16,22} Few studies were also able to identify some patients' characteristics affecting caregiver burden, with some conflicting results.^{12,16,22} A study in Iran identified that caring for younger children is more prone to caregiver burden as younger children are more dependent and need continuous care; however, no association was identified for female or male patients.¹² Disease severity or disability of the patient and duration of illness were also explored in some studies, as it affects the burden of care among caregivers. Chronic illnesses such as cancer, cerebral palsy, congenital anomalies, developmental conditions like ASD and ADHD, and limb dysfunction were some patients' diseases identified, affecting the level of burden among caregivers. The duration of these illnesses and the time of taking care of these patients were also identified as predictors of caregiver burden.^{9,10,12,16}

While caregiver burden for chronic conditions is studied in these previous studies, the present study is meant to provide context and insights into caregiver burden with prolonged hospital stay attendant to their children, specifically diagnosed with a neurologic disorder under long periods of hospital treatment and confinement.

Significance of the Study

This study looks into the level of caregiver burden and its relation to the perception of well-being among caregivers of hospitalized Filipino children with neurological conditions. Understanding caregiver burden and its relation to the caregiver's well-being can shed light on the invisible cost of long-term caregiving. In assessing the factors contributing to caregiver burden, the well-being of caregivers is deemed as important as that of the patients themselves.

For patients, recognizing the pitfalls of caregiving can help prevent fatigue or stress that may cause unintentional neglect of the patient's needs. This helps ensure caregivers are able to provide continuous and consistent care that can lead to better outcomes for patients without sacrificing the caregivers' own well-being.

For caregivers and healthcare providers, understanding the factors that contribute to caregiving burden can help them assess and seek to provide early intervention, guidance, and support in managing the extent of the effects of caregiver burden.

OBJECTIVES

General Objectives

The main objective of the study was to determine the association between caregiver burden and well-being among caregivers of hospitalized Filipino children with neurological conditions.

Specific Objectives

1. To describe the sociodemographic characteristics of caregivers of Filipino children with neurologic conditions hospitalized in a single tertiary center.
2. To identify the prevalence of caregiver burden, based on the Modified Caregiver Strain Index, among caregivers of Filipino children with neurologic conditions hospitalized in a single tertiary center.
3. To assess the perception and to determine the prevalence of well-being among caregivers of Filipino children with neurologic conditions hospitalized in a single tertiary center, using the WHO Well-being Index scoring.
4. To determine which caregiver and patient characteristics are associated with caregiver burden.

Definition of Terms

Caregiver – defined as the person who provides unpaid care to someone, either a relative or a friend with a disability, chronic illness, or other long-lasting health and care needs.²³

Caregiver burden – defined as the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time. It is related to psychological pain, physical, financial, and social strains, dysfunctional family relationships, a sense of hopelessness, and other negative outcomes of care tasks.²⁴

METHODS

Study design

This is a cross-sectional study among primary caregivers of pediatric patients with neurological conditions admitted for a minimum of ten (10) days at the PGH in Manila, Philippines, from December 2024 to January 2025.

The study variables and hypothesized relationships are anchored on the conceptual framework shown in Figure 1,

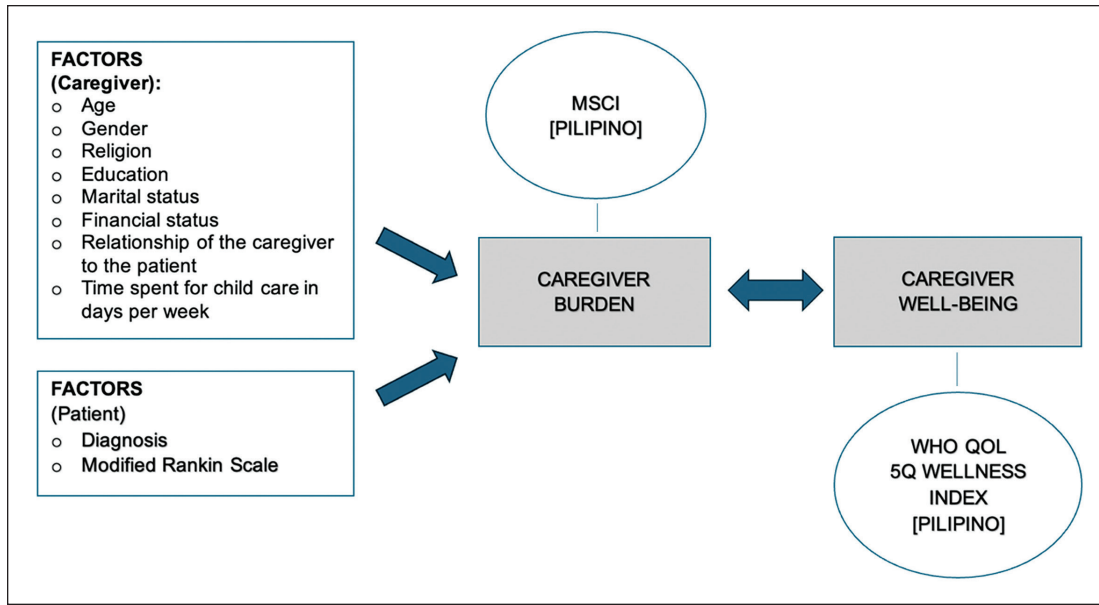


Figure 1. Data Collection Diagram.

which guided the selection of data to be collected and the tools utilized.

The cross-sectional research design was used as this design was deemed the most appropriate approach to examine the relationship between caregiver burden and well-being at a single point in time. This allows the simultaneous measurement of exposure (caregiving burden) and outcome (well-being) among participants, providing a snapshot of their current psychosocial status during hospitalization.

Inclusion criteria

Adult caregivers aged >19 years old of pediatric patients diagnosed with neurologic conditions admitted to PGH ward for at least 10 days. Neurologic conditions included were epilepsy, neurologic infections, neuro-oncology, cerebrovascular diseases, central nervous system (CNS) malformations, autoimmune diseases, neuropsychiatric disorders, and neurologic conditions from post-natal trauma.

Exclusion criteria

The following were excluded from the study:

1. Caregivers of patients hospitalized for fewer than 10 days;
2. Caregivers unwilling or unable to provide informed consent;
3. Caregivers with language barriers that prevented completion of the Filipino or English versions of the questionnaires

The researcher reserved the right to withdraw a participant from the study if (a) informed consent could not be verified, (b) the participant demonstrated significant distress during data collection, or (c) data collection was incomplete despite appropriate support.

Sample Size

Given the average number of pediatric neurology patients admitted in PGH per year of 1,400, the average number of overstaying pediatric neurology patients is 200 per year, and assuming a 20% attrition rate, the required sample size for this study was approximately 97 caregivers, using the simplified Kendall’s Tau formula. This calculation considers a 95% confidence level, a margin of error of 5%, and the finite population correction. The study proceeded to survey 95 caregivers and their patients.

Data Collection

The data collection flow of the study is shown in Figure 2. An approval to conduct the investigation was secured from the research ethics committee of the University of the Philippines, PGH. To be able to identify an eligible caregiver, the list of admitted pediatric patients with neurological conditions was obtained from the censuses of the Division of Pediatric Neurology and the Department of Pediatrics. A total of 186 patients who were admitted from December 2024 to January 2025 were identified. Patients who were admitted for less than 10 days and patients with no consistent caregiver at bedside, such as in the ICU, were excluded. Caregivers who did not give consent were also not included, yielding a total sample size of 95 participants.

A structured socio-demographic data questionnaire was used to collect data from the caregivers of hospitalized children with neurologic conditions. This included the following factors: age, sex, religion, employment, highest educational attainment, marital status, relationship of the caregiver to the patient, and time spent on child care in days per week. Patients’ demographic profile, such as age, neurologic diagnosis, mRS score during admission,

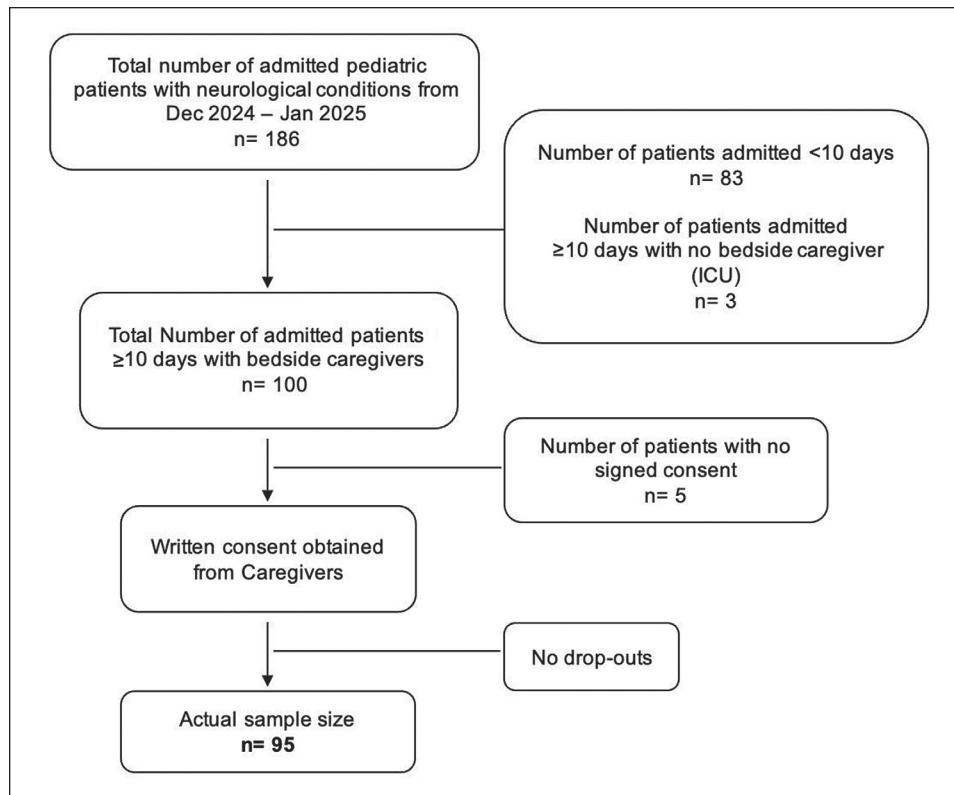


Figure 2. Data Collection Diagram.

and number of hospital days, was obtained from the main census and completed by the investigator. Questionnaires on caregiver burden and well-being index were also answered by the participants. The details on the screening tools used are indicated under outcome measures.

Google Form was used to construct the survey, and participants answered the questionnaire using a tablet provided by the investigator. Written consent was obtained prior conduction of the survey. The participant was asked to step inside an empty isolation room within the pediatric ward to answer the questionnaire in private. In cases of no available separate room, the survey was conducted outside the ward/end of the hallway for privacy. Assigned medical personnel (i.e., a medical intern or clerk) were requested to stay with the patient's bedside while the participant was completing the survey questionnaire. For the participants who were not able to read any part of the questionnaire, the researcher read the questions and recorded their answers. Participants were able to complete survey questions for approximately 15-20 minutes. Individually packed snacks were provided while the participants answered the questionnaire.

The data collection was completed for two months (December 2024 to January 2025), followed by 2 months of analysis and reporting. The compiled responses were recorded in a Microsoft Excel file that was password-protected, using an alphanumeric code as an identifier. All recorded responses were de-identified. Personal identifying marks were not

published. Data will be retained in the secure storage of the Section of Pediatric Neurology for five (5) years following study completion, consistent with institutional ethics guidelines. After this retention period, digital files will be permanently deleted, and physical documents (e.g., signed consent forms) will be shredded under the supervision of the research team.

Outcome Measures

Caregiver burden

The level of caregiver burden was identified utilizing the Modified Caregiver Strain Index-Pilipino (MCSI-P). This tool was designed after the Caregiver Strain Index and was used to screen caregiver burden among Filipino caregivers of chronic and debilitated patients. This self-administered scale consists of eleven statement questionnaires representing 11 areas where caregiver burden may occur: including disruption in sleep, physical burden, family adjustments, competing demands, changes in personal plans, added responsibilities, emotional adjustments, adjustment to patient's personality changes and upsetting behavior, feeling of being overwhelmed, and financial strain. The Modified CSI has slightly better internal reliability ($\alpha = 0.90$) than the original CSI ($\alpha = 0.86$).²⁵ The scoring classification system was as follows: 23 or less = Normal, 24 to 28 = Predisposition to Strain, and 29 and above = Severe Caregiver Strain, where higher

scores depict higher levels of caregiver burden (Appendix A). In this study, caregiver burden was considered when the score reached 24 or above.

Well-being index

The World Health Organization-Five Well-being Index (WHO-5) was developed at the Psychiatric Research Unit, Mental Health Centre North Zealand, Denmark, in 1998. It has been validated in a number of studies with regard to both clinical and psychometric validity.²⁶ The scale has been translated into 29 languages, including Filipino, which was used in this study. This is a self-administered scoring system, consisting of five simple and non-invasive questions measuring the subjective well-being of participants. The scale has adequate validity both as a screening tool for depression and as an outcome measure in clinical trials, and is used as a generic scale for well-being across different settings.²⁶

Because the WHO considers positive well-being to be another term for mental health, the WHO-5 scale contains positively phrased items that relate to mood, vitality, and general interests. The total score ranges from 0 (representing the worst well-being) to 100 (the best imaginable well-being). A score of >50 indicates a better state of well-being or quality of life.²⁶ (Appendix A).

Data Analysis

Descriptive statistics were utilized to summarize demographic data and characteristics of the participants. The association between caregiver burden and well-being of these caregivers was determined using the Pearson R correlation test and univariable logistic regression analysis. The association between the different patient and caregiver characteristics and caregiver burden was also determined using univariable logistic regression analysis. The magnitude of association was presented as an odds ratio and 95% confidence interval. Data analysis was performed using Stat 17. The tests of hypotheses were evaluated with an alpha level set at 0.05.

Ethical Considerations

The study ensured adherence to the 2017 National Ethical Guidelines of Health and Health-related Research. The study protocol was approved by the University of the Philippines-Manila Research Ethics Board (UPMREB 2024-0609-01).

All participants were asked to sign informed consent forms prior to participation. The study was explained prior to signing the informed consent, and voluntary participation was emphasized.

Data collected for this study is kept confidential. All identifiable information and data were given a number code. Only the research team has access to the master list with all identifying information in a password-protected file. All study information was saved in an external drive. This drive was password-encrypted, and the password was only known to the investigators of the study. The research records will be

stored for at least five (5) years following the completion of the study.

The Research Ethics Board will have direct access to the data for checking, without making any of the information public. In the event of any publication regarding this study, the identity of patients will remain confidential.

The research and the questionnaires posed low to no risk to both participants and to the patients involved. A possible risk includes a risk to data privacy. Measures to maintain confidentiality and data privacy were strictly adhered to in order to prevent the risk of possible breach in privacy and sensitive information, given the vulnerable population. In cases of breach of privacy, the Data Privacy Officer will be contacted.

RESULTS

Demographic Characteristics of Patients and Caregivers

A total of 95 caregivers participated in the study from December 2024 to January 2025, consistent with the pre-determined sample size based on the number of annual confined patients at the Pediatric Neurology ward of the PGH. The characteristics of the caregivers and the patients they are taking care of are presented in Tables 1 and 2, respectively.

The mean age of participants was 35.44 ± 9.84 , with the majority of less than 35 years old (53%), most of whom were females (87%) and mothers (79%). Other than mothers, 10% the participants were fathers, while the remaining 10% were either siblings (5.26%), grandparents (2.10%), and uncle/aunt (3.18%). Half of the population was married (49%), while the rest were either single (46%), widowed (2%), or separated (2%). Catholicism was the predominant religion (89%).

In terms of employment, almost half of the participants attending to the patients were unemployed (48%), 32 were employed in either the private or public sector (34%), 15 caregivers were self-employed (16%), and 2 were still students (2%). Regarding educational attainment, most of the caregivers reached a secondary level of education (60%), while only 26% had reached college level.

With only one attendant allowed per patient in the PGH ward, the choice of caregivers was tagged as primary caregivers. At least 10 days of hospitalization were set as the criterion to be included in the study. About 91 caregivers (96%) spent more than 5 days per week providing patient care, while 4 secondary/reliever attendants (4%) stayed in the hospital less than 5 days.

Table 2 presents the demographic and clinical characteristics of hospitalized children with neurological conditions.

Of the 95 patients covered in the surveyed period, 10 categories of neurologic conditions were identified: Neuro-Infectious (25%), Neuro-Oncology (17%), CNS malformations (17%), Epilepsy (15%), Neurologic manifestations of systemic disease (13%), Cerebrovascular diseases (5%), post-natal

Table 1. Caregivers' Characteristics

Caregiver's Characteristics	Frequency (n=95)	Percentage (%)
Age (years)		
<35	50	52.63%
≥35	45	47.37%
Sex		
Male	12	12.63%
Female	83	87.37%
Religion		
Roman Catholic	85	89.47%
Non-Catholic	5	5.26%
Born Again Christian	2	2.10%
Islam	3	3.18%
Others (INC, PMCC, MCGI)*		
Marital status		
Single	44	46.32%
Married	47	49.47%
Widow	2	2.11%
Separated	2	2.11%
Educational attainment		
Elementary	13	13.68%
High school	57	60.00%
College	25	26.32%
Employment status		
Employed	32	33.68%
Self-employed	15	15.79%
Unemployed	46	48.42%
Student	2	2.11%
Relationship to patient		
Mother	75	78.95%
Father	10	10.53%
Relative	10	10.53%
Non-relative	0	0.00%
Time spent in childcare (days)		
<3	0	0.00%
4-5	4	4.21%
>5	91	95.79%

*INC - Iglesia ni Cristo; PMCC - Pentecostal Missionary Church of Christ; MCGI - Members Church of Christ

trauma/ head injuries (5%), Autoimmune disease and Genetic disease and Neuropsychiatric illness (1%).

The majority of the patients were younger than one year (27%), followed by aged 5-9 years old (20%), and 15-18 years old (20%). Males accounted for 57% of the patients, while 43% are females. Among 95 patients included, 14 (15%) were admitted for more than 30 days, while 81 (85%) patients were hospitalized for more than 10 days but less than a month.

The modified Rankin Scale (mRS) for children was used to assess the degree of disability or functionality of patients during admission (Appendix B).²⁷ Out of 95 patients, 33 (35%) had an mRS score >3, indicating moderately severe to severe disabilities, while 24 patients (25%) had mild or no disability, with an mRS score <2. The majority of patients admitted had an mRS score of 3 (33%), suggesting moderate disability. These findings suggest that most patients

Table 2. Patients' Characteristics

Patients' Characteristics	Frequency (n=95)	Percentage (%)
Age (years)		
<1	25	26.32%
1-4	15	15.79%
5-9	19	20.00%
10-14	17	17.89%
15-18	19	20.00%
(mean ± SD) 7.44 ± 6.27		
Sex		
Male	54	56.84%
Female	41	43.16%
Number of hospital admissions		
≤30 days	81	85.26%
>30 days	14	14.74%
mRS score		
0-1	5	5.26%
2	19	20.00%
3	31	32.63%
4	10	10.53%
5	23	24.21%
N/A	7	7.37%
Neurologic conditions		
Epilepsy	14	14.74%
Neuro-Oncology	16	16.84%
Neurologic Infections	24	25.26%
CNS malformations	16	16.84%
Autoimmune diseases	1	1.05%
Cerebrovascular diseases	5	5.26%
Genetic disorders	1	1.05%
Neuropsychiatric conditions	1	1.05%
Systemic illness with neurologic manifestations	12	12.63%
Post-natal trauma/head injury	5	5.26%

Table 3. Level of Caregiver Burden among Caregivers

Caregiver Burden Level	Frequency (n=95)	Percentage (%)
No Strain (≤23)	39	41.05%
Predisposition to strain (24 to 28)	34	35.79%
Severe caregiver strain (≥29)	22	23.16%

experienced moderate to severe functional impairment that may result in prolonged hospital confinement and increased disruption to the caregivers' daily lives, which in turn may be contributing factors to caregiver burden.

Caregiver Burden

The level of caregiver burden was determined by using the Modified Caregiver Strain Index-Pilipino (MCSI-P). The prevalence of caregiver burden among participants characterized as predisposition to strain or severe caregiver strain is 58.95% (95% CI: 49.06% to 68.84%), while 39 participants (41%) did not report caregiver burden (Table 3).

Table 4. Well-being Index among Caregivers

Caregiver Well-being Index	Frequency (n=95)	Percentage (%)
Not impaired (>50%)	8	8.42%
Impaired (≤50%)	87	91.58%

Index of Well-Being of Caregivers

Table 4 presents the index of well-being of caregivers of the pediatric patients with neurological conditions in the study using the WHO-5 Index of Well-being Scale. Among all caregivers, only 8% had a well-being score above 50%, indicating no impairment, while 92% reported impaired well-being (91.58%, 95% CI 84.08-96.29).

Differences in levels of caregiver burden were observed among patients with different neurologic conditions, as shown in Table 5. For patients diagnosed with neurologic infections (TB meningitis, ventriculitis and abscess), burden of care was experienced by 15 caregivers; 8 (8.42%) were predisposed to strain, 7 (7.37%) have severe caregiver strain, while 9 caregivers (9.47%) reported no strain. Neuro-oncologic conditions (brain tumors) and malformations of the CNS (Chiari II malformation) were the second most commonly diagnosed cases admitted in this study. Caregivers of these patients with neuro-oncologic conditions reported no strain 3.16%, predisposition to strain 10.53%, and severe caregiver strain 3.16%, while caregivers of patients with CNS malformations reported 10.53%, 5.25%, and 1%, respectively. For epilepsy patients, a higher proportion of caregivers

(8.42%) reported no strain, while 6.32% experienced severe caregiver strain.

Among the various neurological cases, caregivers of children with neurologic infections (24.21%), CNS malformations (14.74%), and neuro-oncology conditions (13.68%) had the highest proportion of caregivers with impaired well-being or quality of life (Table 5).

Caregivers who reported caregiver burden showed higher odds of having impaired well-being than those without burden (OR 4.91, 95% CI 0.93-25.76, p-value 0.060) (Table 6). On Pearson correlation analysis, the relationship between caregiver burden and caregiver’s well-being showed a very weak negative correlation ($r = 0.168$, 95% CI (-0.3571, 0.0352) as shown in Figure 3. However, there was no sufficient evidence to conclude that the association between the two is statistically significant.

Factors Associated with Caregiver Burden

The different odds of caregiver burden among participants with different patient and caregiver characteristics are shown in Table 7. Due to low sample representation of several categories, all variables were dichotomized in either a logical way or by median split. The association between the different characteristics and caregiver burden was likewise determined by univariable logistic regression analysis. The magnitude of association was presented as an odds ratio and 95% confidence interval.

Table 5. Level of Caregiver Burden and Well-being Index among Caregivers across Different Neurologic Conditions

Neurologic Conditions (n=95)	Caregiver Burden Level			Caregiver Well-being	
	No Strain (≤23)	Predisposition to strain (24 to 28)	Severe caregiver strain (≥29)	Not impaired (>50%)	Impaired (≤50%)
	Frequency (%)				
	39 (41.05)	34 (35.79)	22 (23.16)	8 (8.42)	87 (91.58)
Neurologic infections (n=24)	9 (9.47)	8 (8.42)	7 (7.37)	1 (1.05)	23 (24.21)
Neuro-Oncology (n=16)	3 (3.16)	10 (10.53)	3 (3.16)	3 (3.16)	13 (13.68)
CNS malformations (n=16)	10 (10.53)	5 (5.26)	1 (1.05)	2 (2.10)	14 (14.74)
Epilepsy (n=14)	8 (8.42)	0	6 (6.32)	2 (2.10)	12 (12.63)
Systemic diseases with neurologic manifestations of (n=12)	4 (4.21)	5 (5.26)	3 (3.16)	0	12 (12.63)
Postnatal trauma/ head injury (n=5)	1 (1.05)	3 (3.16)	1 (1.05)	0	5 (5.26)
Cerebro-vascular disease (n=5)	1 (1.05)	3 (3.16)	1 (1.05)	0	5 (5.26)
Auto-immune diseases (n=1)	1 (1.05)	0	0	0	1 (1.05)
Genetic diseases (n=1)	1 (1.05)	0	0	0	1 (1.05)
Neuro-psychiatric disorder (n=1)	1 (1.05)	0	0	0	1 (1.05)

Table 6. Association between Caregiver Burden and Well-being

Burden	Well-being		Odds ratio	95% CI	p-value
	Not Impaired	Impaired			
No strain	6	33	Reference		
Caregiver strain	2	54	4.91	0.93, 25.76	0.060

Table 7. Association between Caregiver and Patient Characteristics and Caregiver Burden

	Odds Ratio (OR)	95% CI	p-value
Caregiver characteristics			
Age: >35yo	1.85	0.80, 4.24	0.149
Sex: Female	0.69	0.19, 2.46	0.563
Marital status: Married	0.88	0.39, 2.00	0.769
Religion: Roman Catholic	1.18	0.50, 2.79	0.702
Education: Above high school level	1.69	0.64, 4.43	0.286
Employment: Unemployed	0.56	0.25, 1.28	0.171
Time spent in childcare: >5 days	0.46	0.05, 4.64	0.514
Patient characteristics			
Age: >10 years old	1.35	0.57, 3.22	0.498
Sex: Female	0.97	0.43, 2.21	0.943
Duration of admission: >30 days	0.92	0.29, 2.89	0.882
mRS score: ≥3	1.06	0.44, 2.52	0.903

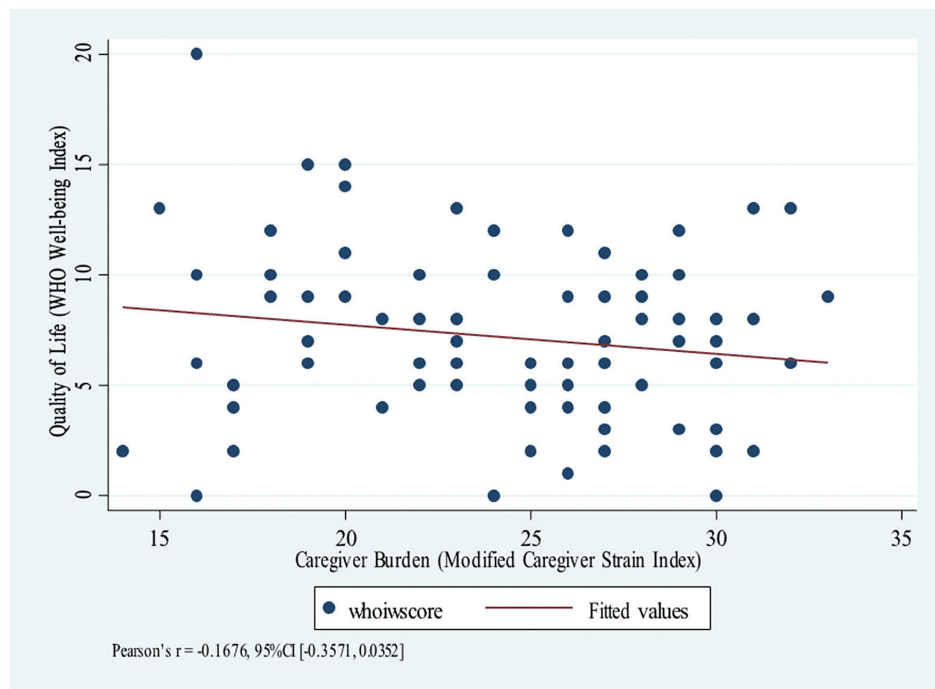


Figure 3. Association between Caregiver Burden and Well-being.

Shown in Table 7 are the identified characteristics of caregivers and patients that are associated with caregiver burden. Among the caregiver’s characteristics, the age of >35 years old and higher educational attainment (above high school level) have increased odds of higher caregiver burden (OR 1.85, 1.69 respectively), compared to younger caregivers (<35 years old) and caregivers with lower educational level. On the other hand, female caregivers are less likely to experience caregiver burden (OR 0.69) compared to male caregivers, as depicted in the present study. Likewise, unemployed caregivers and those caregivers who spent >5 days of caregiving in the hospital (OR 0.56 and 0.46, respectively) have a decreased likelihood of experiencing burden of care. In terms of patients’ characteristics, taking care of older patients (>10 years old)

is 1.35x more likely to be associated with higher caregiver burden than caring for younger children.

While these findings were clinically noteworthy, there is no sufficient evidence to conclude that all these likelihoods were statistically significant.

DISCUSSION

This study was conducted to identify the prevalence of caregiver burden among caregivers of Filipino pediatric patients with neurological conditions and to establish the association between caregiver burden and the caregiver’s well-being.

Caregiver Burden and Factors:

To assess the caregiver burden, the present study used the MCSI-P screening tool, where higher scores depicted higher levels of caregiver burden. In this study, the prevalence of caregiver burden among caregivers of hospitalized patients with neurologic conditions was 59%, wherein 23% reported severe caregiver strain and 36% with predisposition to strain. The prevalence rate is comparable with other studies, both Asian and Western data, with caregiver burden among caregivers of hospitalized children reported at levels ranging from 30% to 55%, while caregiver burden among caregivers of out-patient children was at 24 to 52%.^{9,10,15,16,22,28,29}

In this study, the mothers of hospitalized children were the primary caregivers, mostly belonging to the younger age group, less than 35 years old. This is consistent with other studies where mothers often take the primary caregiving role both for outpatient and inpatient children with medical conditions.^{12,16,18,28,29} While facing emotional, physical, and financial toll of caring for a sick child, being a parent caregiver, either as a mother or father, is not associated with the levels of burden of care.

Several factors were identified in this study that have a higher odds of caregiver burden. In the present study, older caregivers (>35 years old) were more likely to experience caregiver strain than younger participants aged <35 years old. Although there is no sufficient statistical evidence to support this, the findings were consistent with the results of other studies wherein higher levels of burden are found with older caregivers.^{10,11} It was stated that older caregivers may be experiencing their own age-related health problems and declining social support over time, adding to the stress and demands of caregiving.¹¹ However, other studies have reported no relationship between caregiver age and burden, suggesting that coping styles and social support may mitigate age-related vulnerability.^{16,18}

Education and employment status showed mixed trends. In this study, only 26% of caregivers were able to reach college level. Although not statistically significant, caregivers with higher educational attainment (who attained college level) have higher odds of experiencing caregiver strain compared to those who did not complete high school. Furthermore, caregivers who are unemployed and those who have spent a longer time caregiving in the hospital showed lower odds of experiencing caregiver burden. The findings from other studies were reported otherwise, with higher education and employment linked to lower caregiver strain—possibly due to better coping skills, more social support, and access to financial resources.^{11,16,22} In this study, Filipino caregivers have been taking care of their patients even prior to admission to the hospital, and because they do not have other jobs, attending to their patients was their primary role, and subjected to being used to it, which could explain the lesser odds of burden despite staying in the hospital. However, there is no sufficient statistical evidence to support this. Other previous studies obtained no relationship between the caregiver's educational

level and employment and caregiver burden.^{12,18} On the other hand, one's spirituality was not also correlated with caregiver burden in this study, which is consistent with studies done previously.^{11,12,16}

The age of the patient being taken care of was found to be correlated with caregiver burden in the study done by Saeed et al. Increased demands for the care of younger patients lead to a higher caregiver strain. This was in contrast with the findings of the present study, wherein caring for older hospitalized children (more than 10 years old) was more predisposed to caregiver burden. In cases where patients are dependent on basic care activities, caring for an older child requires more physical effort compared with tending to smaller children who are easy to carry, feed, and mobilize. However, findings were statistically not significant. In other studies, patients' age, whether hospitalized or in home care, does not have an effect on the level of caregiver burden.^{18,22}

In the present study, 10 neurological conditions were identified as the reasons for the patients' admission such as (i) neuro-Infectious, (ii) neuro-Oncology, (iii) CNS malformations, (iv) epilepsy, (v) systemic disease with neurologic manifestations, (vi) cerebrovascular diseases, (vii) post-natal trauma/head injuries, (viii) autoimmune disease, (ix) genetic disease and (x) neuropsychiatric conditions. Among these neurologic conditions, caring for patients admitted due to CNS infections and neuro-oncologic conditions showed a higher prevalence of caregiver burden at 15.79% and 13.69%, respectively. These patients have more debilitated illness which required surgical management, multiple diagnostic work-ups, antibiotic completion, and chemo/radiotherapy, which adds to the burden of caregiving.

In addition, these disease-related factors—such as longer hospital stays or more severe neurological disability—were observed to elevate burden, consistent with findings by Saeed et al. and Wei et al.^{10,11} However, the lack of statistical significance in the present study may be due to the small sample size and the resilience of Filipino caregivers, as emphasized by Varona et al., who noted that **collectivist family systems** often distribute caregiving roles and buffer emotional stress.²¹

In other studies, prolonged hospitalization or increased duration of illness were found to have a positive correlation with caregiver burden.^{12,14,16} Increased duration of hospitalization would mean increased time in caregiving, creating additional challenges to caregivers. Factors such as fatigue from disrupted sleep, physical burden from monitoring, feeding, and aid in hygiene care, and prolonged emotional and psychological stress can lead to increased caregiver strain over time. Although in the present study, the duration of hospital stay of patients was not associated with caregiver burden. The patients in this study were admitted to the hospital wards with more than 10 other patients in the same ward with them. Filipino caregivers tend to form relationships and camaraderie with other neighboring caregivers as well as with medical practitioners taking care of their patients. Despite prolonged hospital stay, social isolation, emotional stress,

and occasionally financial burden were alleviated because of the community that they have created with the hospital stay being akin to a home environment, lessening susceptibility to caregiver burden. These social interactions were observed in this study in the wards of PGH.

Because of neurologic conditions of admitted patients, more than 50% of them have moderate to severe disability (mRS score ≥ 3). Although not statistically significant, these populations were found to have a higher tendency toward caregiver strain. In the present study, the patient is completely dependent on the caregiver for basic care and requires continuous medical care, assistance, and monitoring. This finding is comparable to other studies done, where caregivers of hospitalized children with increased disability were more likely to experience caregiver burden.^{18,29}

Globally, comparable studies have confirmed similar patterns. A cross-sectional study among caregivers of patients with neurological disorders found a significant correlation between perceived burden and decreased well-being.³⁰ Likewise, caregivers of patients with advanced cancer reported reduced quality of life associated with increased burden and psychological distress.³¹ These results reinforce that the strain of caregiving consistently undermines psychological health across disease contexts.

Caregiver Burden and Caregiver Well-being

Nearly all caregivers in this study reported impaired well-being, a finding consistent with the studies done by Raina et al. in the United States and Kenis-Coskun et al. in Turkey.^{17,18} The study demonstrated that increased caregiving demands contribute to poorer quality of life.^{10,11,15,16} However, the absence of a significant relationship between caregiver burden and well-being contrasts with earlier studies showing a strong inverse correlation.¹⁴ Particularly in the studies with caregivers to pediatric patients with epilepsy and pediatric patients with cerebral palsy.^{13-15,17,18} Increasing caregiver burden with impact on physical, mental, social, and financial aspects can lead to a decline in the caregiver's overall well-being and quality of life.

The present study used the WHO Well-being Index in measuring the subjective well-being of caregivers. The scale contained items relating to mood, vitality, and general interests. While higher scores mean positive well-being, indicating better quality of life, low scores represent worse well-being or poor quality of life. In this study, the prevalence rate of caregivers with impaired well-being was found to be 92%, and only 8% reported a better subjective sense of well-being. Interestingly, it was found out that for this population with impaired well-being, 96% were caregivers who were predisposed to caregiver burden (OR 0.20, 95% CI 0.04-1.07, p-value 0.060). Although the prevalence rates were high, there was no sufficient evidence to conclude that the association between the two is statistically relevant, where a p-value of 0.050 is considered significant. It was, however, obtained in the study that even caregivers who did

not experience burden in caregiving, 90% of them reported impaired well-being.

Contradictory evidence in the literature may explain the result of this study. For instance, in a Japanese study, social participation was shown to **moderate** the relationship between caregiver burden and subjective well-being—caregivers with strong social engagement maintained high well-being despite high burden.³² Similarly, research among long-term stroke caregivers revealed that **mental health factors such as** anxiety and depression were more strongly associated with well-being than objective measures of burden or patient disability.³³

The resilience of Filipino caregivers could also explain the weak correlation observed. Studies on cultural coping mechanisms have shown that spirituality, family cohesion, and shared caregiving responsibilities serve as protective factors, buffering psychological distress despite high workload.¹⁷ These findings suggest that although the burden of caring in hospitalized settings may contribute to the caregivers' subjective view of overall well-being or quality of life, **caregiver well-being cannot be solely predicted by burden**. Rather, it may depend on social, emotional, and spiritual resources. The discrepancy may reflect the influence of external factors beyond the objective degree of caregiving strain—such as financial stress, unstable employment, prolonged hospital stays, or other problems in the community—that affect caregivers' mental health independently of caregiving intensity. Furthermore, a scoping review by Pinquart and Sörensen in 2011 emphasized that caregiver well-being is influenced by complex interactions between caregiver resilience, social support, and coping strategies, which may vary across cultural contexts.⁵ In the Filipino context, spirituality, family cohesion, and shared caregiving responsibilities likely serve as protective factors that help maintain subjective well-being despite high objective strain.⁹ This resilience may partly explain the absence of a statistically significant correlation between burden and well-being observed in the present study.

Limitations of the Study

The demographics of the study population posed a limitation since the study population is not heterogeneous. Only participants seen at the UP-PGH were included. The small sample size likewise may have affected the results, as it is less likely to capture the full diversity of the population, and findings might only apply to specific individuals in that sample. As the investigator has no control over the types of cases that will be admitted in the wards, involving case-specific neuro conditions to meet the required number will also take more time and resources. However, this is a pilot study. A larger-scale study may be done in the future. This study only intended to establish correlations between risk factors and outcomes, and any causation cannot be established.

CONCLUSION

The present study found that the estimated prevalence rates of caregiver burden among caregivers of hospitalized Filipino children with neurologic conditions was 59%; meanwhile, impaired well-being among caregivers was observed in almost all participants. Although caregivers experiencing burden had higher odds of impaired well-being, the association between the two was not statistically significant. This suggests that while caregiving demands are substantial, other contextual and psychosocial factors—such as financial hardship, emotional resilience, and cultural coping mechanisms—may also influence well-being independently of caregiver burden.

Regarding caregiver and patient characteristics, no demographic or clinical factor, such as age, sex, employment status, or duration of hospital stay, demonstrated a statistically significant relationship with caregiver burden. However, trends suggested that older caregivers and those with higher educational attainment increase the odds of caregiver burden, while unemployed caregivers and those spending more time with their patients reported less strain; these findings were not statistically significant. A higher sample size may help yield a more robust result. The caregivers' subjective view of well-being is generally poor regardless of level of burden, which may suggest that factors other than caregiver burden contribute to perceived well-being beyond the scope of this research.

The data generated from this study will provide healthcare providers as well as caregivers with a better understanding of some factors that may contribute to the burden of care and can help them seek early intervention and support in managing the effects of caregiver burden, which in turn leads to better and consistent care for our patients.

As lives are disrupted over cases of chronic illnesses, including neurological cases in children, interventions such as periodic psychosocial and caring support and development of family-centered care plans can help the caregivers not only cope but also maintain and strengthen their own well-being while taking care of their sick patients.

Recommendations

In this study, the minimum sample size of participants was met based on the annual average of confined pediatric neurological cases and ward beds within a tertiary public hospital setting. However, the study would yield a more robust statistical analysis if a larger pool of participants were considered.

Despite identified limitations, this study provides baseline information about the caregiving situation among confined pediatric patients in a public tertiary hospital in the Philippines. The reported caregiver characteristics emphasized the socioeconomic vulnerabilities that may or may not intensify the burden of care. Studies that will

focus on caregivers of pediatric patients with case-specific neurologic conditions are further recommended, including the association and comparison of the burden of care in diverse conditions with different characteristics. Further investigations, such as a qualitative study with a focus group discussion on caregivers providing interventional or support programs with the aim of identifying caregiver burden and well-being before and after intervention programs, are also recommended.

Statement of Authorship

All authors certified fulfillment of ICMJE authorship criteria.

Author Disclosure

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APPENDICES

Appendix A. Study Questionnaire

A. Socio-demographic profile

Instructions (*Alituntunin*):

Please fill in the blank or check the appropriate spaces for each of the following items:
(*Punan ang mga patlang at i-tsek [✓] ang angkop na sagot sa bawat tanong*):

I. CAREGIVER PROFILE:

AGE (*Edad*): _____

GENDER (*Kasarian*): Male (*Lalaki*) _____ Female (*Babae*) _____

RELIGION (*Relihiyon*): _____

CIVIL STATUS (*Sibil na Katayuan*): Single _____ Married _____ Widow/er _____ Separated _____

EMPLOYMENT (*Trabaho*): Government _____ Private _____ Self-employed _____ Unemployed _____

EDUCATIONAL ATTAINMENT (*Antas ng Pinag-aralan*):

- ___ Elementary Undergraduate
- ___ High School Undergraduate
- ___ High School Graduate
- ___ College Undergraduate
- ___ College Degree
- ___ Master's Degree

RELATIONSHIP TO PATIENT (*Relasyon sa pasyente*): _____

TIME SPENT IN CHILD CARE IN DAYS PER WEEK

(*Oras na ginugol sa pag-aalaga, ilang araw sa bawat linggo*): <3 days _____ 4-5 days _____ >5 days _____

II. PATIENT PROFILE:

AGE (*Edad*): _____

GENDER (*Kasarian*): Male (*Lalaki*) _____ Female (*Babae*) _____

PRESENT WORKING DIAGNOSIS (*Kapasiyahan ng doctor*): _____

MRS score: _____

NUMBER OF HOSPITAL DAYS ADMITTED (*Bilang ng araw sa hospital*): _____

B. Modified Caregiver Stress Index – Pilipino (2007)

LAGYAN NG TSEK [✓] ANG KAHON NG IYONG NAPILING SAGOT	Madalas	Paminsan-minsan	Halos Hindi
	(3)	(2)	(1)
1. Naaabala ang aking pagtulog dahil sa pag-aasikaso sa pasyente.			
2. Ang pag-aalaga sa aking pasyente ay nakakapagod dahil sa pagkarga, pag-alalay at pag-asikaso.			
3. Ang pag-aalaga sa aking pasyente ay nagdulot ng mga pagbabago sa buhay ng aking pamilya dahil sa nagulong pang-araw-araw na gawain.			
4. Nauubos ang aking pansariling oras sa pag-aalaga ng aking pasyente.			
5. Ang pag-aalaga sa aking pasyente ay nagdulot ng mga pagbabago sa aking mga plano sa buhay tulad ng pagpalit o pagtigil sa trabaho o pag-aaral, paglabas-labas, pagbabakasyon, at iba pa.			
6. Bukod sa pag-aalaga sa aking pasyente, mayroon pang dumagdag na responsibilidad na nangangailangan din ng aking oras.			
7. Ang pag-aalaga sa aking pasyente ay nangangailangan ng tibay ng loob dahil sa hindi naiwasang mga alitan at hindi pagkakaunawaan.			
8. Ako ay nalulungkot dahil malaki na ang ipinagbago ng aking pasyente mula ng siya ay magkasakit.			
9. May mga pagkakataon na nauubos ang aking pasensiya at ako ay naiinis dahil sa ikinikilos ng aking pasyente.			
10. Lubos akong nag-aalala kung paano ko makakayanan ang sitwasyong ito.			
11. Malaki na ang aking gastusin dahil sa pag-aalaga sa pasyente.			

Yu-Maglonzo EI, Bautista MT. Modified Caregiver Strain Index (MCSI). University of Santo Tomas. Manila.

C. World Health Organization – 5 (WHO-5) Index of Well-being

WHO-5 Talaan ng Kalidad ng Buhay (1998 na Bersyon) – Salin sa Filipino 2009

Sa bawat pahayag, pumili ng numero na pinakamalapit sa iyong naramdaman noong nakalipas na dalawang linggo. Punahin na ang mas mataas na numero ay indikasyon ng mas mataas na kalidad ng buhay o mas mabuting kalagayan. Halimbawa: Kung ika’y nakaramdam ng kasiyahan at kasiglaan nang higit sa kalahati ng oras sa nakaraang dalawang linggo, markahan ang kahon na may numerong 3 sa may kanang gilid.

	Sa nakalipas na dalawang linggo	Nangyari sa lahat ng panahon	Parating nangyari	Madalas nangyari	Minsan nangyari	Madalang nangyari	Hindi nangyari
1	Ako’y nakaramdam ng saya at sigla	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
2	Ako’y nakaramdam ng kapayapaan at katiwasayan	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
3	Ako’y naging aktibo at masigasig	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
4	Nagising ako nang sariwa at mahimbing ang tulog	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
5	Napupuno ang bawat araw ko ng mga bagay na aking kinagigiliwan	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0

Pagpupuntos: Ang puntos ay nabibilang sa pamamagitan ng pagsasama ng lahat ng nasagutang numero. Ang puntos ay maaaring mula 0 hanggang 25, ang 0 ay nangangahulugang posibleng malalang kalidad ng buhay at ang 25 ay nangangahulugang nang pinaka-magandang kalidad ng buhay. Upang makamit ang porsyento ng puntos na mula sa 0 hanggang 100, ang puntos ay multiplikahin ng 4. Ang porsyento ng puntos na 0 ay ang pinaka malalang posibleng kalagayan, habang ang puntos na 100 ay nagpapahiwatig ng posibleng pinaka-mabuting kalidad ng buhay.

Appendix B. Modified Rankin Scale for Children and Adults

Score	Children	Adults
0	No symptoms at all	No symptoms at all
1	No significant disabilities despite symptoms; behavior appropriate to age and normal further development	No significant disability despite symptoms; able to carry out all usual duties and activities
2	Slight disability; unable to carry out all previous activities, but same independence as other age- and sex-matched children (no reduction of levels on the gross motor function scale)	Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance
3	Moderate disability; requiring some help, but able to walk without assistance; in younger patients adequate motor development despite mild functional impairment (reduction of 1 level on the gross motor function scale)	Moderate disability; requiring some help, but able to walk without assistance
4	Moderately severe disability; unable to walk without assistance; in younger patients reduction of at least 2 levels on the gross motor function scale	Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance
5	Severe disability; bedridden, requiring constant nursing care and attention	Severe disability; bedridden, incontinent and requiring constant nursing care and attention
6	Dead	Dead