

RESEARCH ARTICLE

Caregiver's adherence to out-patient rehabilitation program of children with cerebral palsy in a tertiary government hospital

Kreza Geovien G. Ligaya*, Cynthia D. Ang-Muñoz, Monalisa L. Dungca, Joycie Eulah H. Abiera

Department of Rehabilitation Medicine, Philippine General Hospital, Manila, Philippines

ABSTRACT

Objective: To investigate factors influencing adherence of caregivers to prescribed out-patient management of children with cerebral palsy (CP).

Methodology: This prospective cohort study enrolled 106 children with CP and their caregivers seen at the Philippine General Hospital (PGH) from July 1, 2018 to April 30, 2019 to investigate the association of patient profile, caregiver profile, accessibility of treatment center, and type of therapy, to adherence to out-patient management.

Results: A total of 106 pediatric patients with CP and their caregivers participated in the study with no dropouts observed. Adherence to therapy was defined as completion of patient of at least 50% of the prescribed therapy sessions or completion of at least one set of therapy. Adherence was significantly increased when patients were referred to: (1) physical therapy (OR=34.5, CI 7.21 to 167, $p<0.01$); (2) occupational therapy (OR=31.67, CI 3.84, $p=0.01$); and (3) speech and language therapy (OR=28.12, CI 5.33 to 148, $p<0.01$). Adherence decreased as the number of types of therapies prescribed increased [(OR=0.83, CI 0.24 to 2.79, $p=0.76$ for those with 2 therapies); (OR=0.45, CI 0.09 to 2.14, $p=0.32$ for those with 4 therapies)].

Conclusion: Caregiver's adherence to out-patient rehabilitation program was seen to be significantly influenced by the type of therapy the patient with CP was referred to undergo (i.e., PT, OT, SLT).

Introduction

One out of seven or approximately 5.1 million Filipino children have disabilities [1]. According to the Philippine Statistics Authority, almost 19% of all persons with disabilities (PWDs) belonged to the 0 to 14 years age group, with the highest number in the 5 to 19 years age group [2]. One such disability is cerebral palsy (CP), which is defined as a group of permanent, non-progressive disorders that had occurred in the developing fetal or infant brain affecting posture, movement and motor coordination, causing limitation in activities and restriction in participation [3,4]. Children with CP can also present with sensory, cognitive, communication, behavior and medical problems and secondary musculoskeletal complications. CP is the most common disabling motor disorder affecting children with incidence of 2.0 to 3.0 per 1,000 in the general population [3]. It is the major developmental disability in children affecting function [5]. There is however paucity on the local incidence or prevalence of CP. The 2000 Philippine Disability Survey reported crude prevalence rate of disability at 2.9% with movement disability as the most frequent, and 3.35% prevalence of developmental impairments including CP [6].

CP remains to be one of the most commonly seen out-patient conditions at the Department of Out-Patient Service (DOPS) of the Department of Rehabilitation Medicine (DRM) up to the present. This condition requires long-term care that includes frequent visits to the hospital for consultations and therapies, provision of maintenance medications to address tone abnormalities and/or seizure, and prolonged use of assistive devices for proper positioning and mobility [2,7,8]. With this multifaceted approach to management comes multiple factors influencing the adherence of caregivers.

The 2001 World Health Organization (WHO) study on the adherence to long-term therapies investigated on knowledge, understanding and perception of the disease by the patient and the caregiver, as well as importance of the therapies (medical and physical), degree of psychological condition (presence or absence of depression), and economic status [9]. Adherence is defined by WHO as the "extent to which a person's behavior – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" [9]. This requires the patient's (in this case, the caregiver's) agreement to the recommendation. This active participation differentiates adherence to treatment from compliance, which is defined as the passive following of provider's orders [10]. In developed countries, adherence rate is at 50%, and this is even lower in developing countries due to limited health resources and inequities in access to health care

[4,9-11]. The psychological status of the caregiver, translated into depression and anxiety, also affects adherence to therapy. In a study conducted in Türkiye by Alintag *et al.*, it was observed that mothers of children with CP manifested depression and anxiety and these worsened as the physical condition of their children regressed [12,13]. Adherence to management is important to assist the caregiver and the patient in achieving the medical and rehabilitation goals.

CP can cause multiple problems in body structure and function leading to limitation in activities and in participation. Presence of personal factors and environmental factors can further complicate the medical and functional issues. Seeing the complexity of the medical case of the pediatric patient with CP, the multifaceted condition also brings about multifaceted effects to the caregiver [14-16]. Hence, the various factors influencing a caregiver that may bring about drastic impact in the management of the patient with CP are: (1) medical/ psychological (anxiety/ depression/ coping strategies, other medical conditions); (2) altered body structure and function (none if caregiver is generally healthy); (3) limitation in activity (none if caregiver is generally independent in performing activities of daily living); (4) limitation in participation (unable to go to work, decreased amount of time given to care for other members of the family); (5) personal factors (psychosocial support, family dynamics, transportation factors); and (6) environmental factors (educational attainment, socioeconomic status, relationship to patient, time/ availability, therapy factors (cost of therapy, schedule of therapy), and satisfaction with service providers (PT, OT, SLT, psychologist, physiatrist, nurse, other rehabilitation personnel).

Since most children with CP seen at the DRM are functionally dependent on their caregivers, adherence to out-patient management is largely caregiver dependent. This study aimed to investigate and determine the factors influencing adherence of caregivers to prescribed out-patient management of children with CP. These factors include: patient factors (height and weight,

Corresponding author's email address:

krezaligaya@yahoo.com.ph

Keywords: adherence, cerebral palsy, caregiver

Date submitted: October 1, 2024

Date accepted: March 8, 2025



type and severity of CP, cognitive ability), caregiver factors (education, employment and financial capacity, psychosocial support), accessibility of treatment center (proximity of patient home to the institution, number of rides, fare), and complexity of management.

Methodology

Study Design and Settings

This is a prospective cohort study design. This study involved children with CP and their respective caregiver(s) who were seen and managed at the DRM-DOPS in PGH from July 1, 2018 up to April 30, 2019. Data collection was completed in July 2019.

Study Participants

This study used purposive sampling of 106 pediatric patients with CP and their caregivers from the DRM-DOPS in PGH. For a child with multiple eligible caregivers, only the primary caregiver was recruited. Criteria for the pediatric patients were: (1) 2 years old and less than 18 years old, (2) diagnosed with CP [with cranial computed tomography (CT) scan or magnetic resonance imaging (MRI)], (3) with presumptive diagnosis of CP still undergoing diagnostic procedures, with history and clinical manifestations compatible with CP, (4) "old" (previously seen, at least once, by the resident) or "new" (referred by other services in PGH and other institutions and initially seen by the resident) patients of the DRM-DOPS in PGH, and (5) brought to PGH by their caregivers for therapy for at least 6 sessions within 6-week period from start of initial treatment. Pediatric patients were excluded if they: (1) have non-permanent and/or progressive motor disorder, (2) with hereditary conditions, and (3) undergoing rehabilitation management solely in other institutions.

Caregivers were selected as participants if they were: (1) of any relationship with the patient (parents, relatives, hired caregiver, adoptive parents, and others) who spent at least 8 hours a day for at least 5 days a week and who are responsible for the daily care of the patient; (2) staying with the patient for the next 6 months; (3) may not be the main provider of the child's immediate basic needs; (4) willing to bring the patient to PGH on a regular basis for rehabilitation management; and (5) willing to participate in the study. They were excluded if they were: (1) caring for the patient less than 8 hours a day, (2) not medically stable, (3) providing the rehabilitation of the child solely in other institutions, and (4) not able to read and/or write as these are needed skills in filling up the daily patient record or diary.

Study Procedure

The study was approved by the University of the Philippines Manila Research Ethics Board (UPMREB-2017-566-01). Patient and/or caregiver recruitment and interview were conducted by the principal investigator (PI) or research assistant (RA) at the DRM-DOPS. Each patient was assessed and managed by the DRM-DOPS service resident rotators and referred the patient to the PI or RA if inclusion criteria were met. After securing informed consent from the caregiver and/or assent form from the cognizant pediatric patient, caregiver interview was conducted immediately and recorded in the data collection form (DCF). The DCF was adapted from the studies of Hebreo and Obispo and Lim-Dungca that included severity of disability using the Gross Motor Function Classification System (GMFCS) score, Manual Ability Classification System (MACS) score, and Functional Mobility Scale (FMS) score systems [14,17]. The GMFCS is a classification for mobility status of children with CP, with or without the use of an assistive device such walkers or wheelchairs [18].

The severity of illness of the patient in terms of comorbidities was also included. Evaluation of the patient and primary caregiver and review of medical records to extract information regarding medications, orthoses and treatment sessions were performed. The caregiver answered a set of self-administered questionnaires on depression level, family support level, coping health inventory, self-assessment, and presence of strain [19-23]. The caregiver was given a weekly therapy attendance sheet and caregiver diary to record medications administered to the patient, patient's use of orthosis, and patient's attendance to treatment sessions with the different therapy sections: PT, OT, SLT, and psychological therapy. Patient was followed-up at the DRM clinic a week after the end of the therapy session. The PI monitored the adherence of the caregiver by collecting the caregiver diary from the PT

Section weekly. Attendance to therapies was counterchecked using the database of each therapy section by the therapist-in-charge.

Patients and their caregivers were considered dropped from the study if the patient was admitted in a hospital for any medical condition. They were recruited back upon follow-up at the DRM-DOPS. The following were also dropped: (1) caregivers were not able to schedule their patients for therapy after recruitment, (2) patients did not follow-up, and (3) caregivers were not able to answer calls when called back. The paramedical sections at the DRM, PGH have varying treatment protocols. Prescribed program per patient is 4 to 6 therapy sessions for PT done once or twice weekly, 6 therapy sessions for OT done once weekly, and 6 therapy sessions for SLT done once weekly. Sessions with the psychologists may be once only if referred only for psychometric evaluation or can be 4 to 6 sessions if for behavioral and psychological therapy. After the patient's schedule was given, the therapist instructed the caregiver on the rules and regulations of the therapy section to prevent early termination of treatment. Participants were removed from the roster of a particular therapy section if the child: (1) had missed two consecutive treatment sessions, or (2) had any unexcused absence wherein the caregiver failed to notify the therapist. Patient participation in the study was terminated after completion of a set of a particular therapy. Each patient was followed up at least 1 month after enrollment in the study to assess adherence to the prescribed therapy.

Statistical Analysis

Adherence to therapy was defined as the following: (1) the ability to bring the patient to attend any of the therapies (e.g., PT, OT, SLT, psychological therapy) for at least 50% of the prescribed frequency of therapy session, or (2) the ability to bring the patient to complete at least one set of therapy. Non-adherence was operationally defined as: (1) if patients were brought to therapy less than 50% of the prescribed frequency of therapy session, or (2) if the patient was taken out from more than one type of therapy due to repeated absences. Adherence to medications was defined as ability of the caregiver to administer prescribed medications on time while adherence to orthosis wear was defined as ability of the caregiver to facilitate prescribed wearing of splint or orthosis, both based on the caregiver diary and follow up interview.

Descriptive statistics were used to summarize the demographic and clinical characteristics of the caregivers and their respective patients. Frequency and proportion were used for categorical variables. Logistic regression was used to determine differences in selected variables between adherent and non-adherent caregivers. Odds ratio and its 95% confidence interval (CI) was used to determine the association of clinical characteristics to the adherence of the caregiver. Missing variables was neither replaced nor estimated. Null hypotheses were rejected at 0.05 level of significance. STATA 13.1 statistical software was used for data analysis.

Results

Results were obtained from 106 pediatric patients with CP and their respective caregivers. There were no dropouts noted. Majority of the caregiver participants (69%) were in the adherent group. There were no adverse events observed during the course of the study.

Patients' Profile

The pediatric patients' profile is presented in Table 1. Most patients in both adherent and non-adherent groups were predominantly males (66%), 2 to 6 years old (57%), belonged to the most severe level GMFCS Level 5 (42%), and of the spastic type (92%). Overall, most patients weighed less than 15 kg (59%), were at least 100 cm tall (53%), and with body mass index (BMI) of <15 kg/m² (59%). Majority (65%) did not present with additional condition other than CP. The most common associated condition seen was seizure/epilepsy (48% in adherent; 50% in non-adherent).

Adherence Pattern and Patients' Profile

Adherence by caregivers to out-patient therapy program was noted to increase as the patient gets older (OR=1.42, confidence interval (CI) 0.59 to 3.41, $p=0.13$), but decreased with the severity of CP (at GMFCS 5, OR=0.46, CI 0.17 to 1.25, $p=0.13$). The presence of other medical conditions also decreased adherence with one accompanying condition (OR=0.68, CI 0.27 to 1.74, $p=0.43$) and with two accompanying conditions (OR=0.47, CI 0.12 to 1.96, $p=0.30$). Patients' age, severity of CP, and presence of associated conditions did not significantly

influence caregiver adherence. On the other hand, adherence was noted to increase when patients were small enough to be transported by caregivers [weighed <15 kg (OR=1.07, CI 0.46 to 2.49, $p=0.92$), was <100 cm tall (OR=1.29, CI 0.57 to 2.94, $p=0.55$), and with BMI of <15 kg/m² (OR=1.56, CI 0.66 to 3.68, $p=0.31$)]. For mode of mobility, majority were carried (53%). Adherence was increased when patient was carried (OR=1.08, CI 0.47 to 3.46, $p=0.86$), was ambulatory (OR=1.57, CI 0.64 to 3.86, $p=0.33$), or was transported in a stroller (OR=2.18, CI 0.44 to 10.7, $p=0.34$), but decreased adherence when patient used wheelchair (OR=0.48, CI 0.15 to 1.55, $p=0.22$). Only approximately 39% of children in both groups were attending either regular or special education (SPED) school. Adherence increased when patients were enrolled in SPED (OR=2.17, CI 0.65 to 7.25, $p=0.21$) but decreased when patients were enrolled in regular school (OR=0.95, CI 0.33 to 2.72, $p=0.92$). Patients' weight, height, BMI, modes of mobility, and schooling did not significantly affect caregiver adherence.

Caregivers' Profile

Table 2 summarizes the caregivers' profile. Overall, most caregivers were more than 20 years old, with mean age of 36.97 ± 11.79 years, female (94%), and mostly mothers (78%).

Adherence Pattern and Caregivers' Profile

Caregivers who were 21 to 30 years old were 39% more likely to adhere to therapies (OR=1.39, CI 0.52 to 3.74, $p=0.73$) while female caregivers were 57% less likely to adhere (OR=0.43, CI 0.05 to 3.79, $p=0.44$). Mothers were 4% less likely to adhere (OR=0.96, CI 0.35 to 2.61, $p=0.94$). Age, gender, and relationship to patient did not significantly influence caregiver adherence.

All caregivers were educated. Majority finished secondary level of education in both groups (51%) but there were more non-adherent caregivers with tertiary level of education (45%). Only 9% in both groups finished primary level. Caregivers who attained secondary level were 11% more likely to adhere compared to those with primary level (OR=1.11, CI 0.25 to 4.88, $p=0.89$). In contrast, caregivers with higher level (tertiary) were 23% less likely to adhere (OR=0.77, CI 0.17 to 3.43, $p=0.73$). Overall, most caregivers were not employed (72%). There was better adherence among unemployed caregivers (OR=1.71, CI 0.65 to 4.51, $p=0.28$). Majority (60%) had one person employed in the family. There were two families in the adherent group with no working member in the family. Families with one person working showed decreased adherence when compared to families with unemployed members (OR=0.72, CI 0.30 to 1.72, $p=0.46$). Level of education, employment status, and number of working individuals did not significantly affect caregiver adherence.

Most caregivers in both groups (33%) belonged to the PhP 10,001 to 20,000 monthly income group. There were more families in the non-adherent group with less than PhP 5,000 monthly income (30%) while more adherent families reported more than PhP 30,000 monthly income (12%). There was better caregiver adherence with higher family income (OR=8.18, CI 0.87 to 76.58, $p=0.06$ for income more than PhP 30,000). For social support, most caregivers in both groups (59%) reported two parents involved in childcare. Caregivers with spouse have better adherence (OR=2.50, CI 0.33 to 19.13, $p=0.38$) than single-parent caregivers supported by relatives (OR=1.92, CI 0.24 to 15.26, $p=0.54$). Most caregivers in both groups (71%) were noted to have little knowledge of their patients' conditions. Caregivers who were more knowledgeable were 25% less likely to adhere (OR=0.75, CI 0.31 to

Table 1. Pediatric Patients' Profile and Comparison of Clinical Characteristics between Adherent and Non-adherent Groups

Variables	Total (n=106)	Adherent (n=73)	Non-adherent (n=33)	Crude odds ratio (95% CI)	P-value
	Frequency (%); Mean $\pm$ SD; Median (IQR)				
Age of the child (years)	6.22 $\pm$ 3.75	6.58 $\pm$ 3.95	5.42 $\pm$ 3.15	1.09 (0.97 to 1.23)	0.146
2 to 6	60 (56.60)	38 (52.05)	22 (66.67)	(reference)	-
7 to 12	38 (35.85)	27 (36.99)	11 (33.33)	1.42 (0.59 to 3.41)	0.432
13 to <18	8 (7.55)	8 (10.96)	0	-	-
Gender of the child					
Male	70 (66.04)	49 (67.12)	21 (63.64)	(reference)	-
Female	36 (33.96)	24 (32.88)	12 (36.36)	0.86 (0.36 to 2.03)	0.726
GMFCS level	3.21 $\pm$ 1.74	3.05 $\pm$ 1.72	3.55 $\pm$ 1.79	0.85 (0.66 to 1.08)	0.180
1 (least affected)	31 (29.25)	23 (31.51)	8 (24.24)	(reference)	-
2	14 (13.21)	10 (13.70)	4 (12.12)	0.87 (0.21 to 3.57)	0.846
3	7 (6.60)	5 (6.85)	2 (6.06)	0.87 (0.14 to 5.40)	0.881
4	10 (9.43)	10 (13.70)	0	-	-
5 (most affected)	44 (41.51)	25 (34.25)	19 (57.58)	0.46 (0.17 to 1.25)	0.126
CP types					
Spastic	98 (92.45)	68 (93.15)	30 (90.91)	1.36 (0.31 to 6.06)	0.687
Others	8 (7.55)	5 (6.85)	3 (9.09)	(reference)	-
Accompanying conditions					
No additional condition	69 (65.09)	50 (68.49)	19 (57.58)	(reference)	-
With one accompanying condition	28 (26.42)	18 (24.66)	10 (30.30)	0.68 (0.27 to 1.74)	0.427
With two accompanying conditions	9 (8.49)	5 (6.85)	4 (12.12)	0.47 (0.12 to 1.96)	0.303
Weight (kg)	18.28 $\pm$ 13.07	19.88 $\pm$ 14.71	14.74 $\pm$ 7.39	1.04 (0.99 to 1.09)	0.075
< 15 kg	63 (59.43)	43 (58.90)	20 (60.61)	1.07 (0.46 to 2.49)	0.924
$\geq$ 15 kg	43 (40.57)	30 (41.10)	13 (39.39)	-	-
Height (cm)	103 $\pm$ 0.24	105 $\pm$ 0.23	98 $\pm$ 0.27	3.32 (0.58 to 19.16)	0.180
< 100 cm	50 (47.17)	33 (45.21)	17 (51.52)	1.29 (0.57 to 2.94)	0.547
$\geq$ 100 cm	56 (52.83)	40 (54.79)	16 (48.48)	(reference)	-
Body Mass Index (BMI)	17.48 $\pm$ 13	16.86 $\pm$ 8.27	18.85 $\pm$ 19.97	0.99 (0.96 to 1.02)	0.475
< 15 kg/m ²	63 (59.43)	41 (56.16)	22 (66.67)	1.56 (0.66 to 3.68)	0.310
$\geq$ 15 kg/m ²	43 (40.57)	32 (43.84)	11 (33.33)	(reference)	-
Mobility					
Ambulatory	36 (33.96)	27 (36.99)	9 (27.27)	1.57 (0.64 to 3.86)	0.330
Carried	56 (52.83)	39 (53.42)	17 (51.52)	1.08 (0.47 to 3.46)	0.855
Stroller	11 (10.38)	9 (12.33)	2 (6.06)	2.18 (0.44 to 10.7)	0.337
Wheelchair	13 (12.26)	7 (9.59)	6 (18.18)	0.48 (0.15 to 1.55)	0.219
Schooling					
Special Education (SPED)	20 (18.87)	13 (17.81)	7 (21.21)	2.17 (0.65 to 7.25)	0.206
Regular school	21 (19.81)	17 (23.29)	4 (12.12)	0.95 (0.33 to 2.72)	0.924
Not attending school	65 (61.32)	43 (58.90)	22 (66.67)	(reference)	-

1.83, $p=0.53$). There were no significant associations between income, social support, and knowledge of the condition and caregiver adherence.

The psychological and psychosocial profiles of the caregivers were also analyzed (Table 3). Adherence was noted to increase by: (1) 1% to 4% for every increase in test score in the Coping Health Inventory for Parents (CHIP) Scale [higher test score indicates better perception of the caregiver of the helpfulness provided for by the presence of family, friends and other external help with adherence; OR=1.01, CI 0.95 to 1.07, $p=0.85$; OR=1.04, CI 0.94 to 1.16, $p=0.42$]; and (2) 4% for every increase in test score in the caregiver self-assessment questionnaire [higher score is indicative of high degree of distress that the caregivers were not previously aware

of; OR=1.04, CI 0.93 to 1.16, $p=0.52$]. On the other hand, adherence was noted to decrease by: (1) 2% for every increase in test scores for the Beck Depression Inventory [higher score is indicative of increasing risk of having depression; OR=0.98, CI 0.95 to 1.02, $p=0.32$]; and (2) 1% for every increase in test score for caregiver strain [higher score is indicative of increase in experienced strain; OR=0.99, CI 0.86 to 1.11, $p=0.77$]. However, an increased score in the Modified Family Support Scale [MFS: higher score reveals higher perceived support from family and other people in the society; OR=0.99, CI 0.97 to 1.02, $p=0.87$] did not result in increased adherence to out-patient program, with caregivers noted to be 1% less likely to adhere to out-patient program. All variables analyzed did not significantly influence caregiver adherence.

Table 2. Caregivers' Profile and Comparison of Clinical Characteristics between Adherent and Non-adherent Groups

Variables	Total (n=106)	Adherent (n=73)	Non-adherent (n=33)	Crude odds ratio (95% CI)	P-value
	Frequency (%); Mean ± SD; Median (IQR)				
Age of caregiver (years)	36.97 ± 11.79	36.95 ± 12	37.03 ± 11.52	0.99 (0.97 to 1.03)	0.638
< 20	3 (2.83)	3 (4.11)	0	-	-
21 to 30	34 (32.08)	23 (31.51)	11 (33.33)	1.39 (0.52 to 3.74)	0.729
31 to 40	34 (32.08)	26 (35.62)	8 (24.24)	2.17 (0.76 to 6.14)	0.881
> 40	35 (33.02)	21 (28.77)	14 (42.42)	(reference)	-
Sex of the caregiver					
Male	6 (5.66)	5 (6.85)	1 (3.03)	(reference)	-
Female	100 (94.34)	68 (93.15)	32 (96.96)	0.43 (0.05 to 3.79)	0.443
Relationship					
Mother	83 (78.30)	57 (78.08)	26 (78.79)	(reference)	-
Father	6 (5.66)	5 (6.85)	1 (3.03)	2.28 (0.25 to 20.51)	0.462
Grandmother	11 (10.38)	6 (8.22)	5 (15.15)	0.55 (0.15 to 1.96)	0.354
Grandfather	1 (0.94)	0	1 (3.03)	-	-
Aunt	4 (3.77)	4 (5.48)	0	-	-
Guardian	1 (0.94)	1 (1.37)	0	-	-
Mother	83 (78.30)	57 (78.08)	26 (78.79)	0.96 (0.35 to 2.61)	0.935
Educational attainment					
Primary	10 (9.43)	7 (9.59)	3 (9.09)	(reference)	-
Secondary	54 (50.94)	39 (53.42)	15 (45.45)	1.11 (0.25 to 4.88)	0.886
Tertiary	42 (39.62)	27 (36.99)	15 (45.45)	0.77 (0.17 to 3.43)	0.733
Employment status					
Employed	30 (28.30)	23 (31.51)	7 (21.21)	(reference)	-
Unemployed	76 (71.70)	50 (68.49)	26 (78.79)	1.71 (0.65 to 4.51)	0.279
Number of working individuals					
None	2 (1.89)	2 (2.74)	0	(reference)	-
1 person	64 (60.38)	42 (57.53)	22 (66.67)	0.72 (0.30 to 1.72)	0.464
More than 1 person	40 (37.74)	29 (39.73)	11 (33.33)	-	-
Family income (Php)					
Less than 5,000	21 (19.81)	11 (15.07)	10 (30.30)	(reference)	-
5,001 to 10,000	34 (32.08)	26 (35.62)	8 (24.24)	2.95 (0.92 to 9.49)	0.069
10,001 to 20,000	35 (33.02)	23 (31.51)	12 (36.36)	1.74 (0.58 to 5.26)	0.325
20,001 to 30,000	6 (5.66)	4 (5.48)	2 (6.06)	1.82 (0.27 to 12.17)	0.538
More than 30,000	10 (9.43)	9 (12.33)	1 (3.03)	8.18 (0.87 to 76.58)	0.065
Social support					
1 Parent/Caregiver	1 (0.94)	1 (1.37)	0	(reference)	-
2 Parents	63 (59.43)	45 (61.64)	18 (54.55)	2.5 (0.33 to 19.13)	0.377
1 Parent with relatives	38 (35.85)	25 (34.25)	13 (39.39)	1.92 (0.24 to 15.26)	0.536
2 Parents with relatives	4 (3.77)	2 (2.74)	2 (6.06)	-	-
Knowledgeable					
Yes	31 (29.25)	20 (27.40)	11 (33.33)	0.75 (0.31 to 1.83)	0.534
No	75 (70.75)	53 (72.60)	22 (66.67)	(reference)	-

Table 3. Caregivers' Profile and Comparison of Test Results between Adherent and Non-adherent Groups

Tests	Total (n=106)	Adherent (n=73)	Non-adherent (n=33)	Crude odds ratio (95% CI)	P-value
	Frequency (%); Mean $\pm$ SD; Median (IQR)				
Beck* score	13 (5 to 26)	12 (4 to 26)	16 (7 to 27)	0.98 (0.95 to 1.02)	0.319
MFS†	42.20 $\pm$ 16.59	42.03 $\pm$ 15.75	42.59 $\pm$ 18.61	0.99 (0.97 to 1.02)	0.871
CHIP1‡	42.20 $\pm$ 16.59	39.21 $\pm$ 6.40	38.94 $\pm$ 7.33	1.01 (0.95 to 1.07)	0.848
CHIP2	44.65 $\pm$ 7.37	44.48 $\pm$ 7.55	45.03 $\pm$ 7.05	0.99 (0.93 to 1.05)	0.721
CHIP3	17.78 $\pm$ 3.88	17.99 $\pm$ 4.05	17.33 $\pm$ 3.47	1.04 (0.94 to 1.16)	0.421
Caregiver strain	5.13 $\pm$ 3.28	5.07 $\pm$ 3.47	5.27 $\pm$ 2.87	0.99 (0.86 to 1.11)	0.766
Caregiver self-assessment score	5 (2–9)	5 (2–9)	5 (2–8)	1.04 (0.93 to 1.16)	0.521

*Beck Depression Inventory; †Modified Family Support Scale; ‡Coping Health Inventory for Parents Scale

Accessibility of Therapy Center

Table 4 shows the effect of accessibility on adherence to out-patient management. Most caregivers in both groups (88%) brought their patients to PGH exclusively for therapeutic management with 12% also bringing the children to other institutions for therapy. Enrolling at another institution other than PGH for additional therapies increased their adherence to out-patient management in PGH by 2% (OR=1.02, CI 0.29 to 3.58, $p=0.98$) but there was no significant association. Majority (66%) lived in Metro Manila with mostly non-adherent caregivers (70%). In contrast, there were more adherent caregivers living outside Metro Manila (36%). Caregivers living within Metro Manila as compared to outside Metro Manila were noted to have decreased adherence by 21% (OR=0.79, CI 0.32 to 1.90, $p=0.59$). For both groups, majority (51%) spent less than PhP 150 for fare per visit. There were more non-adherent caregivers needing to spend more than PhP 300 per visit (33%). Increase in travel expenses decreased adherence by 44% (OR=0.56, CI 0.21 to 1.48, $p=0.24$ for fare more than PhP 300). Majority in both groups (51%) reported taking single ride to PGH compared to 13% taking three rides. Only 3% (in non-adherent) to 4% (in adherent) owned vehicles. Commute requiring more than three rides decreased adherence by 17% (OR=0.83, CI 0.24 to 2.84, $p=0.76$). There were no significant differences found between residence location, travel expenses, and number of rides to the treatment center and caregiver adherence.

Financial resources of the families are presented in Table 5. Overall, majority (52%) did not have government health insurance from Philippine Health Insurance Corporation (PHIC or PhilHealth), with only 10% who availed of the insurance benefits. Benefits for out-patient services were not available at the time this study was conducted. Majority in both groups (99%) paid out of pocket for out-patient expenses. There were no significant associations between PHIC utilization and out-of-pocket expenses with caregiver adherence ($p=0.68$ and $p=0.31$, respectively). Some families also tapped other government institutions (i.e., Department of Social Welfare and Development, local government units) for financial assistance.

Type of Therapy

Caregiver adherence to therapies and other rehabilitation interventions prescribed is summarized in Table 6. Overall, most caregivers were adherent to their patients' PT (83%) and SLT (51%) but not to OT (only 43%) and

psychological therapy (only 16%). Adherence of caregivers was noted to be significantly increased when patients were referred to: (1) physical therapy (OR=34.5, CI 7.21 to 167, $p<0.01$); (2) occupational therapy (OR=31.67, CI 3.84, $p<0.01$); and (3) speech and language therapy (OR=28.12, CI 5.33 to 148, $p<0.01$). In contrast, caregiver adherence decreased as the number of types of therapies prescribed increased. Caregivers were 17% less likely to adhere when patients were prescribed with two types of therapies (OR=0.83, CI 0.24 to 2.79, $p=0.76$) while those prescribed with four types of therapies were 55% less likely to adhere (OR=0.45, CI 0.09 to 2.14, $p=0.32$). The number of types of therapies prescribed however did not significantly influence caregiver adherence.

For administration of prescribed medications, all non-adherent caregivers reported adherence to administering medications as compared to only 84% in the adherent group. In contrast, more caregivers in the adherent group (57%) were adherent to use of orthotic or other assistive devices. Caregivers whose patients were prescribed with devices showed increased adherence to wearing time (OR=2.67, CI 0.55 to 12.88, $p=0.22$) but there was no significant association.

Discussion

Cerebral palsy is one of the top chronic pediatric illnesses being managed by the Department of Rehabilitation Medicine (DRM) of the Philippine General Hospital (PGH) with 21.7% of pediatric patients diagnosed with CP based on the DRM-DOPS 2012 census. There is limited published literature regarding adherence to prescribed out-patient management of patients diagnosed with CP in the Philippines. The DRM PGH 2016 census showed: (1) approximately 10% of caregivers of children scheduled for physical therapy (PT) did not attend any session, 50% attended 1 to 2 times only, 35% attended 3 to 5 times, and less than 10% had completed the prescribed 6 sessions; (2) 30% of patients for occupational therapy (OT) attended 1 to 2 times, 45% 3 to 5 times, and only 25% completed the prescribed 6 sessions; and (3) out of the 34 patients with CP for psychological evaluation, only 23 adhered to their schedule. The Speech and Language Therapy (SLT) Section only had an in-patient dysphagia referral listing for August to December of 2016 that showed 46 out of 256 (18%) pediatric patients (diagnoses not indicated) were seen at the Section. A focus group discussion with caregivers of patients with CP conducted at the DRM, PGH in 2016 showed that financial difficulties was the

Table 4. Accessibility of Treatment Center and Comparison of Clinical Characteristics between Adherent and Non-Adherent Groups

Variables	Total (n=106)	Adherent (n=73)	Non-adherent (n=33)	Crude odds ratio (95% CI)	P-value
Frequency (%); Mean $\pm$ SD; Median (IQR)					
Rehab center					
PGH	93 (87.74)	64 (87.67)	29 (87.88)	(reference)	-
PGH and other institution	13 (12.26)	9 (12.33)	4 (12.12)	1.02 (0.29 to 3.58)	0.976
Within Metro Manila	70 (66.04)	47 (64.38)	23 (69.70)	0.79 (0.32 to 1.90)	0.593
Outside Metro Manila	36 (33.96)	26 (35.62)	10 (30.30)	(reference)	-
Travel expenses (fare per visit, Php)					
<150	54 (50.94)	39 (53.42)	15 (45.45)	(reference)	-
150 to 300	25 (23.58)	18 (24.66)	7 (21.21)	0.99 (0.34 to 2.85)	0.984
>300	27 (25.47)	16 (21.92)	11 (33.33)	0.56 (0.21 to 1.48)	0.241
Number of rides to Rehabilitation Center					
1 ride	54 (50.94)	37 (50.68)	17 (51.52)	(reference)	-
2 rides	38 (35.85)	27 (36.99)	11 (33.33)	1.13 (0.45 to 2.79)	0.795
3 rides	14 (13.21)	9 (12.33)	5 (15.15)	0.83 (0.24 to 2.84)	0.763
Vehicle ownership	4 (3.77)	3 (4.11)	1 (3.03)	1.37 (0.14 to 13.70)	0.788

Table 5. Financial Resources of Caregivers between Adherent and Non-adherent Groups

Sources	Total (n=106)	Adherent (n=73)	Non-adherent (n=33)	P-value
Frequency (%); Mean $\pm$ SD; Median (IQR)				
PhilHealth				0.682
Yes	11 (10.38)	7 (9.59)	4 (12.12)	
No	55 (51.89)	40 (54.79)	15 (45.45)	
Unused	40 (37.74)	26 (35.62)	14 (42.42)	
Own money	105/106 (99.06)	73/73 (100.00)	32/33 (96.97)	0.311
DOH*	1/106 (0.94)	1/73 (1.37)	-	-
DSWD†	5/106 (4.72)	4/73 (5.48)	1/33 (3.03)	-

*DOH: Department of Health; †DSWD: Department of Social Welfare and Development

Table 6. Complexity of Treatment and Comparison of Clinical Characteristics between Adherent and Non-adherent Groups

Variables	Total	Adherent	Non-adherent	Crude odds ratio (95% CI)	P-value
	Frequency (%); Mean $\pm$ SD; Median (IQR)				
Type of therapy and splint use					
PT (N=101)	(N=101)	(n=71)	(n=30)		
Yes	84 (83.17)	69 (97.18)	15 (50.00)	34.5 (7.12 to 167)	<0.001
No	17 (16.83)	2 (2.82)	15 (50.00)		
OT (N=60)	(N=60)	(n=40)	(n=20)		
Yes	26 (43.33)	25 (62.50)	1 (5.00)	31.67 (3.84)	0.001
No	34 (56.67)	15 (37.50)	19 (95.00)		
SLT (N=53)	(N=53)	(n=33)	(n=20)		
Yes	27 (50.94)	25 (75.76)	2 (10.00)	28.12 (5.33 to 148)	<0.001
No	26 (49.06)	8 (24.24)	18 (90.00)		
Psychological therapy (N=11)	(N=11)	(n=6)	(n=5)		
Yes	2 (18.18)	2 (33.33)	0	-	-
No	9 (81.82)	4 (66.67)	5 (100)		
Number of therapies (N=106)	(N=106)	(n=73)	(n=33)		
Single therapy	26 (24.53)	20 (27.40)	6 (18.18)	(reference)	-
2 therapies	30 (28.30)	22 (30.14)	8 (24.24)	0.83 (0.24 to 2.79)	0.757
3 therapies	40 (37.74)	25 (34.25)	15 (45.45)	0.5 (0.16 to 1.52)	0.223
4 therapies	10 (9.43)	6 (8.22)	4 (12.12)	0.45 (0.09 to 2.14)	0.316
Adherence to medicines (N=27)	24 (88.89)	16 (84.21)	8 (100.00)	-	-
Adherence to orthosis (N=37)	19 (51.35)	16 (57.14)	3 (33.33)	2.67 (0.55 to 12.88)	0.222

topmost reason for not bringing their children to the hospital for therapies and follow-up. Lack of data on reasons for poor adherence by caregivers to scheduled out-patient therapies and follow-up leads to difficulty in determining the impact of rehabilitation interventions on functional outcomes and in weighing the cost/benefit ratio for the prescribed programs.

Foreign studies on adherence and compliance for managing patients with CP and other pediatric disorders showed congruent results with our study which strengthens the need to address the factors affecting adherence for medical and paramedical out-patient management. Adherence in rehabilitation perspective is defined as an “active, voluntary collaborative involvement of the patient (caregiver in this study) in a mutually acceptable course of behavior to produce a desired preventive or therapeutic result” [24]. Rehabilitation adherence is not limited to medicine adherence but encompasses: “attending clinical appointments, active participation in rehabilitation activities during clinical appointments, carrying out home therapies, avoiding potentially harmful and contraindicated activities, and wearing of protective or therapeutic devices” [24].

The operational definition of adherence in this study is the patient's completion of at least 50% of the prescribed frequency of therapy sessions or completion of at least any one set of therapy if with multiple therapies prescribed. It has been reported that the adherence rate in developed countries is 50% and may be lower in developing countries [9]. We used this figure as cut-off for this study which is lower compared to similar caregiver studies on children with CP with 70% or more completed sessions considered as adherent [15,16]. Our study showed there were more adherent caregivers which concurred with the study conducted in Kenya where 90% of 14 parent participants were adherent to outpatient OT sessions despite lack of knowledge on CP and its treatment process [25]. Similarly, Usman et al reported that 53% of 60 Nigerian caregivers were adherent to physiotherapy services in the hospitals with level of education, marital status, knowledge of the condition, and socioeconomic class of caregivers significantly affecting adherence [15]. In contrast, only 34% of 225 Bangladeshi caregivers maintained adherence to physiotherapy appointments in the hospital with socioeconomic status, number of siblings, consultation with doctors, parents' education, and several other factors significantly affecting caregiver adherence [16]. In contrast, Basaran et al reported that there were more adherent (65%) Turkish caregivers to home exercise program, noting that severity of functional limitation of children with CP seems to increase caregiver adherence while caregiver exhaustion and burnout have negative impact on adherence [26]. Lillo-Navarro et al reported that parents' adherence to home exercise program for children with physical disabilities depends on the physiotherapists' teaching style and characteristics of the exercise program [27]. Adherence is influenced by social and economic factors, health system-related factors, therapy-related factors, disease-related factors, and patient-related factors [9].

Patients' Profile

The children in our study were mostly 2 to 6 years old in both adherent and non-adherent groups. This is similar to the study by Islam where most children were 12 to 60 months old but predominantly younger aged 12 to 24 months old (25%) and 25 to 36 months old (22%) [16]. In our study, inclusion criterion was 2 years old to less than 18 years old. Although signs of CP appear during the first two years of life, many children are not diagnosed until two years or later [29]. In contrast, children in our study were older than most patients in the Biwott study who were 6 to 24 months old [25]. Biwott surmised that there were more young children for OT because the average child with CP is diagnosed approximately at 12 months and younger patients were lighter to carry to the hospital. Adherence rate for older children decreased because they may have improved and no longer required therapy, had undergone other interventions, had grown making transport difficult, had passed on or had migrated to other locations [25]. This is contradictory to our finding of 42% increase in caregiver adherence as children get older. This may be due to observed improvement in children or continuation of therapy intervention when enrollment in SPED schools was not feasible.

Our study showed that most patients were male, similar to Hebreo et al's local study on profile of children with CP with 58% males [14]. Islam also reported male predominance but only in the non-adherent group (58%) [16]. There is higher incidence of CP among males. This may be related to a “greater biological vulnerability in terms of cerebral structure, hormone protective role, and genetic polymorphism” [29].

Majority in our study presented with GMFCS Level 5 and spastic type, wherein these results were similar to the results of the studies of Hebreo et al [quadriplegia (36%), spastic CP (50%)], and Islam [quadriplegia (44%)] [14,16]. Spastic CP is the most common type affecting approximately 80% of individuals with CP [30]. A recent study using a CP register from low- and middle-income countries (LMICs) also showed male predominance (61%), overall prenatal and perinatal etiologies (87%), with 79% children with spastic CP, and 73% in GMFCS levels III to V [31]. Basaran et al reported that majority in the good adherence group had spastic quadriplegia and GMFCS Level V (25%) while in the poor adherence group, most had spastic diplegia and GMFCS Level I [26]. On the contrary, our study showed more patients with GMFCS Level 5 in the non-adherent group while the adherent group had more patients with GMFCS Level 1. Children with increased severity that have restricted mobility (i.e., requiring more effort to transport to therapy centers), or with slow or minimal improvement over time may be barriers to caregiver adherence. Islam reported there were more children in the adherent group (50%) who were prescribed with assistive device while only 44% had assistive device in the non-adherent group [16].

Most children with CP that were included in our study did not have other associated conditions. For those with associated conditions, the most common condition in both groups was seizure/epilepsy. Our findings are similar to Islam's study where most children (72.4%) did not present with other diseases; but among those with reported associated diseases, pneumonia (12.0%), seizure (10.7%) and asthma (5.8%) were the most common [16]. Additionally, 45.3% of children in this study presented with speech disability (28.9%), intellectual disability (16.9%), hearing disability (5.3%), and vision problem (4%). Basaran et al reported bladder and bowel problems (53.1%), speech impairment (52.1%), and intellectual impairment (50.0%) in the good adherence group in contrast to intellectual impairment, visual impairment, and bladder and bowel problems (each at 47.1%) in the poor adherence group [26]. Hebreo et al also revealed associated problems, namely: feeding (100%), communication (63%), and seizure (58%) [14]. Our study showed decreased adherence when patients have associated conditions. Islam reported that among those with concomitant conditions, there was similar number of adherent (28%) and non-adherent (28%) caregivers but there was no significant association [16]. Although CP is a non-progressive disorder, children may develop associated conditions that can potentially lead to progressive complications further challenging a child's limitation in activities and participation [3,9]. There should be anticipatory monitoring to optimize function as the child grows; thus, the need for continuing adherence to therapy and medical consultations.

Majority in our study, mostly in the non-adherent group, did not attend school. This finding is similar to Islam's study where 65.8% of children older than 60 months old did not go to school [16]. In Islam's study, mean age was 49.90 ± 29.50 months (4 years); children above 5 years old are eligible for schooling. In contrast, our patients were older with mean age of 6.22 ± 3.75 years and school age starts at 7 years old in the local public schools. In our study, there was almost the same number of children who were enrolled in regular school and SPED school. In contrast, Hebreo *et al.* reported slightly more children with CP aged ≥ 4 years old (29%) who were enrolled in SPED school [14]. Caregiver adherence in our study was better when children were enrolled in SPED school. It was presumed that the SPED school administration may be more supportive of children with special needs being pulled out from class to undergo hospital-based therapy. Presence of disability may be a barrier in provision of education to children with disability (CWD). As of 2010, there are at least 375,952 school-age CWD in the Philippines, among which only 1 in every 3 children is in school and only 1 in every 7 is enrolled in SPED class [32]. The Philippine Statistics Authority (PSA) reported that among 1.4 million Filipinos with disabilities, 300,000 are school-age children [33]. The Department of Education (DepEd) reported in 2011 that only 5,916 CWD are included in regular classes [33]. Challenges in providing optimal education to CWD include financial difficulty, bullying, accessibility, and availability of SPED schools in the community. Children with CP in other LMICs also lack access to rehabilitation and educational services [31]. In contrast, a study conducted in Hong Kong showed that among 219 children with CP in mainstream schools, 26% received educational support and 61% were provided out-patient therapy support compared to 12% receiving both support services and 26% not receiving support for both education and therapy [34]. Children with disabilities in other countries have equal opportunity to education as able-bodied children as mandated by laws such as the Individuals with Disabilities Education Act in the United States and the Compulsory Education Act in Singapore [35,36]. In the Philippines, the recent passing into law mandating inclusive education for learners with disabilities (Republic Act 11650) is a promising step in providing equal educational services to CWD [37].

Caregivers' Profile

Majority of the adherent caregivers in our study were 31 to 40 years old while most non-adherent caregivers were older than 40 years old. Our findings are similar to Usman et al's study where most adherent Nigerian caregivers (47%) were slightly younger who were 20 to 40 years old while there were older caregivers (36% in 40 to 60 years old and 11% in 60 to 80 years old) who were non-adherent ($p < 0.05$) [25]. On the contrary, Islam reported that mothers in both groups were >30 years old with most adherent caregivers in the 26 to 40 years age group [16]. Poorer adherence by older caregivers may be due to personal health related issues and the need for another adult companion to help transport the child to the treatment center.

Our study showed predominance of female caregivers who are mothers of children with CP in both groups which was also observed in other foreign studies [15-26]. These studies reported that women were expected to be more adherent and assume more of the responsibilities of nurturing and caring for

children [25,26,38]. Despite the nurturing characteristics of mothers, our study showed high rate of non-adherence among mothers. Out of the 33 non-adherent caregivers, 25 were mothers of which nine mothers have patients who were bigger and heavier, were carried or wheelchair-borne, and would spend fares of more than PhP 150 per institution visit. Islam reported that most caregivers were mothers with increased non-adherence across all age groups: for ≤ 30 years old (68%) and for >30 years old (32%) but this was not statistically significant [16].

All caregivers in our study were educated with most adherent caregivers completing secondary level of education. Caregivers with tertiary level of education were less likely to adhere compared to those who attained lower level of schooling. One caregiver participant with masteral degree stated that work is a primary factor for her poor adherence to therapy. In contrast, Usman et al reported that most non-adherent caregivers (41%) had non-formal education while majority in the adherent group had BSc/HND level or secondary level of education (both at 36%) ($p < 0.05$) [15].

The employment of caregivers also affects adherence. In our study, there were more unemployed caregivers but with most families having at least one person in the household working in both groups. This finding is similar to Hebreo et al's study where majority were mothers who were younger than 20 years old (38%), with high school education (42%), and housewives or "house husbands" who were unemployed (72%) [14]. When primary caregivers are employed, it is more difficult for them to take a leave from work to bring patients to therapy [25].

Hebreo *et al.* reported in 2017 that majority (67%) of the families had gross monthly family income of PhP 5,000 to 10,000 [14]. This is similar to our study with monthly family income of PhP 5,001 to PhP 20,000. Moreover, there were more non-adherent families with monthly income below PhP 5,000 compared to more than PhP 30,000 among adherent families. Our findings are similar to the Nigerian study where most adherent caregivers belonged to the upper socio-economic status (43%) while most non-adherent caregivers were in the lower socio-economic status (47%) ($p < 0.05$) [15]. The 2018 PSA report revealed that the average annual family income is PhP 313,000 (or PhP 26,083.33 a month) [39]. Caregivers in our study reported back pains from prolonged carrying of their children during commute and need for a companion on follow-up or therapy schedules resulting to absence from work and loss of income for their family. Taking care of CWD requiring long-term therapy can take a heavy toll on the family with suboptimal income and living in the city with high cost of living, ultimately affecting caregiver adherence.

Several studies have shown that strong family support system is essential in the care of CWD. In our study, both parents were involved in the care of the child showing better caregiver adherence. Likewise, Biwott reported that married parents were more adherent to treatment than single parents as the former have better social and financial support from the spouse that can lessen the burden of care [25]. A local study by Lasco et al revealed that the experience of living with CWD is shared by the Filipino family, especially by the parents, from "coming to terms with a disability" to "adaptation;" thus, the need for family-centered approach in caring for a CWD [40]. Raina et al reported that higher family functioning, fewer child behavior problems, and less caregiving demands were associated with better psychological and physical health of caregivers [41]. Social support to carers of children with special needs could be provided through support group among caregivers of CWD, caring training on care of children with CP, and workshop intervention for mothers of CWD to alleviate the burden on caring [41-43].

Ignorance to treatment is an obstacle to adherence [25]. When a caregiver gained knowledge of the patient's condition and proper understanding of the importance of each stage of medical and paramedical management, adherence tends to increase even if it was difficult to bring the patient to the treatment institution. Moreover, adherence is improved when a caregiver would observe improvement, no matter how minimal. Most caregivers in our study had little or no knowledge on the CP condition at the start. In comparison, Usman et al reported that most adherent caregivers (82%) were knowledgeable of the CP condition while 72% of non-adherent caregivers were not knowledgeable ($p < 0.05$) [15]. In another study, more adherent caregivers were knowledgeable on physiotherapy (71%) [16]. Usman et al reported that level of education, marital status, knowledge of the child's condition and socioeconomic class significantly affect adherence ($p < 0.05$) while age of caregivers has no significant association with adherence ($p > 0.05$) [15]. Our study however showed caregivers with knowledge were 25% less likely to

adhere. For those caregivers who had adequate knowledge upon initial interview, gain of new knowledge may be little as compared to caregivers who had little knowledge at the outset. This may explain the observed high number of caregivers with little or no knowledge who were adherent as compared to those who were initially knowledgeable. In Biwott's study, despite inadequate knowledge prior to diagnosis of CP, majority reported that clinicians explained the condition to them and, thus, improving adherence [25]. Adherence to administration of medicine and to wearing of orthosis is also improved when caregivers are knowledgeable as they can appreciate the effects of each intervention on their patients.

The psychosocial condition of the caregiver also affects adherence. When more family members or friends provide encouragement and assistance in provision of multiple needs of both caregiver and patient, a positive health outcome was observed [25]. In addition, married parents were noted to be more adherent to treatment and were able to attend therapies regularly with assurance of support from partners on daily basis. Our study showed similar results wherein adherence decreased with increasing risk for depression and caregiver strain. Presence of good family financial and emotional support and better psychological condition for caregivers increased their adherence. As the caregivers received more help from the family, stress, depression, and anxiety decrease; caregiver strain is decreased; perception of social support improves; and eventually improves adherence to multiple treatments advised for the patient's care [10,12,25]. However, result for Modified Family Support Scale (MFS) showed a slight deviation from what was expected (e.g., higher perceived family support increases adherence) in our study. On further analysis, most non-adherent caregivers despite having high MFS scores were taking care of heavy patients who were mostly carried and with GMFCS Level 5. Fare cost, number of rides, and place of residence were also factors affecting their non-adherence. Marron et al reported that self-efficacy showed negative linear association with burden while degree of disability and depression showed positive linear association with burden [44]. Chiluba and Moyo recommended that burden inflicted on caregivers of children with CP should be addressed to improve the quality of care of these children [45].

Accessibility of Therapy Center

Our study showed that accessibility influenced adherence directly. Seventy (70) caregivers were from within Metro Manila with 12 of them needing at least three rides and 25 caregivers spending at least PhP 150 travel expenses. However, only seven of the 25 caregivers were from the City of Manila. Forty-five percent (45%) of the caregivers from the City of Manila had at most PhP 10,000 monthly income and 62% from other cities in the metropolitan had at most PhP 10,000 monthly income. When caregivers had to travel more distance and to pay higher fares with low family income, their adherence was observed to decrease even if most were living within Metro Manila because they would need to spend more time and money for the commute. Similarly, Islam reported significant association between location of participants' residence ($p < 0.01$), distance between residence and treatment center ($p < 0.01$), and traveling time ($p < 0.01$) and adherence but not for traveling cost ($p = 0.09$) and changing the vehicle ($p = 0.07$) [16].

Service patients in PGH pay PhP 130 per therapy session for "Class C" and PhP 50 for "Class D." Despite the minimal cost, children with CP will require long-term therapy escalating its cost. Aside from direct cost of treatment, families also need to pay for transportation and food expenses and caregiver cost. There are also indirect costs such as lost productivity of the employed caregiver and/or adult companion on therapy days. Despite presence of other government institutions, e.g., Department of Social Welfare and Development (DSWD), Department of Health (DOH), Philippine Charity and Sweepstakes Office (PCSO), the difficulty in completing requirements to apply for financial assistance adds to the inaccessibility of health care. Additionally, PHIC, the government insurance company, only provides in-patient health benefits. The unavailability of medical service for out-patient needs further makes health care inaccessible. However, the PHIC has recently implemented the Z Benefits for Children with Disabilities to address out-patient expenses of CWD, improving accessibility to rehabilitation care (PhilHealth Circular No. 2016-0032) [46]. The PGH is one of the treatment hubs for CWD providing services for vision, hearing, mobility, and developmental conditions as recommended by a physician [46]. Accessibility in terms of ease in application by PHIC members and availability of services in the community is essential; lest, families will continue to pay out of pocket. In 2010, the PSA reported that the average household size is 4.6 persons [47]. The average annual Filipino family income as of 2018 is PhP 313,000 with average of savings of PhP

75,000 and average annual expenditure of PhP 239,000 with food ranking first (42.6%) while health expenses ranked 8th (2.7%) [48]. There is a dire need to provide financial assistance not only from the medical institution but also from other governmental and non-governmental agencies.

Type of Therapy

The DRM of PGH offers comprehensive pediatric rehabilitation for CWD including PT, OT, SLT, Psychology, prosthetic, and orthotic services. In the 2017 profile study on children with CP managed in PGH, these patients underwent PT most frequently (64%), followed by OT (29%), SLT (26%) and psychological therapy (10%); while resting hand splint (26%) and posterior ankle splint (43%) were the most frequently prescribed orthoses [14]. This finding is similar to our study with most caregivers being most adherent to PT but followed by SLT and OT. It is said that the more complicated the treatment program, the more difficult it is for the caregiver to keep up with appointments for therapy and follow-up. In our study, there was significant decrease in adherence with increasing number of types of therapy prescribed. There was only one study that reported on caregiver adherence to various types of out-patient therapy for CP similar to our study, while the other studies were on either PT or OT [15,16,25].

In our study, caregivers of patients who underwent PT, OT and SLT were 34.5 times, 31.7 times, and 28.1 times more likely to be adherent, respectively. The increased caregiver adherence to PT services in DRM, PGH could be attributed to the increased accessibility of the service with more staff physical therapists and short waiting time. There was also increased adherence to OT and SLT despite the longer waiting time with fewer staff. Our finding is contrary to Biwott's study wherein long waiting time increases inaccessibility to attainment of health care for patients [26]. Increased caregiver adherence to OT may be secondary to caregiver knowledge of management or noted improvements on patient skills after completion of OT sessions. Similarly, most patients referred for SLT were for dysphagia management; hence, increased caregiver adherence to SLT. Rezaie and Kendi reported that therapy-related factors [assessment tools, type of intervention(s), length of treatment] and therapist-related factors (clinical competence, communication skills and job satisfaction) can be modifiers to caregiver adherence [49].

More caregivers were adherent to administration of medications to their patients, but correlation cannot be drawn in our study. In contrast, Halpern et al reported poor adherence (50% of treatment periods) to various oral spasticity medications regardless of spasticity index and underlying neurologic conditions [50]. Improving patient's compliance through patient education such as use of compliance aids, proper motivation and support may improve medication adherence [51]. Medication compliance or adherence can be influenced by interaction of patient's "soft" factors (e.g., beliefs, health knowledge and relationship with healthcare provider) which may be additive or synergistic or at times antagonistic [52]. More caregivers were noted to be adherent to wearing of orthotic devices. It was reported in a 2009 local study that caregivers of low-income find it difficult to adhere to additional management (e.g., use of special devices or equipment) as it is an added burden to their patient care [17]. However, caregivers in our study reported that their doctors' explanation on the importance of management and observed improvements in their patients made them adhere more. This observation is also supported by the findings in the Kenya study [25].

The difficulty in the management of CP is not lack of "cutting-edge" technology, medicine, or sophisticated equipment to carry out procedures; rather the challenges are caused by less tangible issues whose overall effect is an ineffective management process [53]. Hence, attention should be given on issues such as non-adherence to clinical processes, late diagnosis, unaffordability, and unavailability of professional care for patients with CP [53].

Conclusion and Recommendations

Caregiver's adherence to out-patient rehabilitation program was seen to be significantly influenced by the type of therapy the patient with CP was referred to undergo (*i.e.*, PT, OT, SLT). The rest of the factors investigated such as patient-related factors, caregiver-related factors, and accessibility of treatment center did not show significant influence to caregiver adherence.

Limitations of our study are non-inclusion of variables that may affect caregiver adherence, namely: (1) number of siblings of patients; (2) work

experience and marital status which can provide information on caregiver wellness, support status, etc.; (3) availability of other relative or personnel to take care of other children at home when the caregiver had to bring the patient for therapy; (4) profile of the patients' fathers that may influence financial capability and family support system; (5) physician's relationship to patient and parent, and (6) communication between clinical team and patient's caregiver on the child's condition and its management. This study investigated caregivers in a single institution in a relatively short duration. The observed trend in this study may be different if caregivers were to be followed up for longer period to detect caregiver fatigue, as CP is a lifelong disability needing prolonged rehabilitation interventions. Hence, longer study period is recommended to address caregiver fatigue. It is also recommended that a multi-center study be conducted to be more reflective of the general population of interest across different regions in the country.

Another focus group discussion with caregivers can be conducted to get in-depth feedback from all participants after partial or full adherence to prescribed therapies to explore other factors that can influence adherence to different medical and paramedical therapies prescribed. Lastly, to assess the association between duration of center-based intervention and caregiver adherence, it is recommended that patients and their caregivers be categorized as "old" (or returning) and "new" patients to allow subgroup analyses of other drivers and barriers on adherence.

Habilitation of children with CP is a long-haul process requiring multiple types of therapy and anticipatory management over a protracted period. Adherence to rehabilitation therapies and related regimen is one of the important parameters to positive treatment outcomes. Addressing the basic needs of these children such as accessibility to therapy centers with options for referral to facility in the community or telerehabilitation; judicious prescription of therapy programs with regular monitoring; financial assistance; and caregiver support are recommended solutions to sustain caregiver adherence to prescribed rehabilitation programs to improve treatment outcomes and provide quality care for these children.

References

- United Nations Children's Fund (UNICEF) – Philippines. (2018) No child left behind: Study calls for better care of children with disabilities.
- Republic of the Philippines Philippine Statistics Authority. (2020) Persons with disability in the Philippines (Results from the 2010 Census)
- Rosenbaum P, Paneth N, Leviton A, *et al.* (2006) A report: the definition and classification of cerebral palsy. *Dev Med Child Neurol Suppl.* 2007;109:8-14.
- Gillette Children's. (2016) Cerebral Palsy.
- Jones MW, Morgan E, Shelton JE, Thorogood C. (2007) Cerebral palsy: introduction and diagnosis (part I). *J Pediatr Health Care.* 21(3):146-52. doi: 10.1016/j.pedhc.2006.06.007.
- Guzman C, Baltazar J, Dy-Mancao B, Miguel-Baquilod M, Trinidad F. (2000) The Philippine disability survey: a collaborative study. Department of Health, University of the Philippines-Manila Development Foundation.
- Niedzwecki C, Roge D, Schwabe A. (2016) Cerebral palsy. Braddom's physical medicine and rehabilitation, 5th ed. Philadelphia: Elsevier Inc, pp. 1053-1070.
- National Library of Medicine (National Center for Biotechnology Information). (2017) Chronic disease definition
- Sabaté S, Bengoa R, Yach D, *et al.* (2003) Adherence to long-term therapies: evidence for action. World Health Organization
- Compas B, Jaser S, Dunn M, Rodriguez E. (2012) Coping with chronic illness in childhood and adolescence. *Annu Rev Clin Psychol.* 8: 455-40. [SEP]
- Fielding D, Duff A. (1999) Compliance with treatment protocols: interventions for children with chronic illness. *Arch Dis Child.* 80:196–200. [SEP]
- Altindag O, Iscan A, Akcan S, Koksall S, Ercin M, Ege L. (2007) Anxiety and depression levels in mothers of children with cerebral palsy. *Turk J Phys Med Rehab.* 53(1):22-4.
- Dambi JM, Jelsma J, Mlambo T. (2015) Caring for a child with cerebral palsy: The experience of the Zimbabwean mothers. *African Journal of Disability* 4(1), Art#168. Doi:10.4102/1jod.v4i1.168.
- Hebreo AR, Ang-Muñoz C, Abiera JE, Dungca M, Mancao B. (2017) Profile of pediatric patients with cerebral palsy at the Department of Rehabilitation Medicine, Philippine General Hospital. *Acta Medica Philippina* 52(4):289-99.
- Usman MY, Abdulmanaf A, Abba MA, Kani MZ. (2017) Factors affecting adherence to physiotherapy appointments for caregivers of children with cerebral palsy in Kano metropolis. *Arch Physiother Glob Res* 21(2):13-9.
- Islam MR. (2019) Factors influencing the utilization of physiotherapy services among the caregiver of the cerebral palsy children at Protibondhi Seba-O-Sahajjo kendro in Bangladesh. Department of Physiotherapy, Bangladesh Health Professions Institute (BHPI).
- Obispo MF, Lim-Dungca M. (2009) A preliminary study on the factors affecting compliance to home program on neurodevelopmental techniques (NDTs) among motor delay patients. *PARM Proceedings.* 3(1):76-88.
- Wikipedia. (2020) Gross motor function classification system.
- UC Davis Health ASAP Resources. (2016) Beck's depression inventory.
- Taylor M. (1999) Family support and resources in families having children with disabilities. ERIC. ED434430:1-33. Appendix D E
- UCLA. (2016) Coping health inventory for parents (CHIP) scale.
- Caregivers library. (2016) Caregiver self-assessment questionnaire.
- Shirley Ryan Ability Lab. (2016) Caregiver Strain Index.
- Kolt GS, Brewer BW, Pizzari T, Schoo AMM, Garrett N. (2007) The Sports Injury Rehabilitation Adherence Scale: a reliable scale for use in clinical physiotherapy. 93:17-22.
- Biwott LC. (2014) Factors influencing cerebral palsy caregivers' adherence to occupational therapy in Usain Gishu County: A case of Moi Teaching and Referral Hospital. L50/61238/2013. (Masteral thesis)
- Basaran A, Karadavut K, Uneri S, Balbaloglu O, Atasoy N. (2014) Adherence to home exercise program among caregivers of children with cerebral palsy. *Turk J Phys Med Rehab.* 60:85-91.
- Lillo-Navarro C, Medina-Mirapeix F, Escolar-Reina P, Montilla-Herrador J, Gomez-Arnaldos F, Oliveira-Sousa SL. (2015) Parents of children with physical disabilities perceive that characteristics of home exercise programs and physiotherapists' teaching styles influence adherence: a qualitative study. *Journal of Physiotherapy* 61:81-6. <http://dx.doi.org/10.1016/j.jphys.2015.02.014>
- Eunice Kennedy Shriver National Institute of Child Health and Human Development. (2020) What are the early signs of cerebral palsy?
- Romeo DM, Sini F, Brogna C, *et al.* (2016) Sex differences in cerebral palsy on neuromotor outcomes: a critical review. *Dev Med Child Neurol.* 58:809-13. DOI:10.1111/dmcn.13137
- CDC. (2020) Cerebral palsy (CP).
- Jahan I, Muhit H, Hardianto D, Laryea F, Chhetri AB, Smithers-Sheedy H, *et al.* (2021) Epidemiology of cerebral palsy in low- and middle-income countries: preliminary findings from an international multi-centre cerebral palsy register. *Dev Med Child Neurol.* 63(11):1327-26. Doi:10.1111/dmcn.14926. PMID: 34031872.
- Save the children. (2020) Everyone deserves to learn.
- Philippine News Agency. (2020) Wider access to education for children with disabilities urged.
- Yam W, Chan H, Tsui K, *et al.* (2016) Prevalence study of cerebral palsy in Hong Kong children. *Hong Kong Med J.* 12(3):180-4. [SEP]
- US Department of Education. (2022) About IDEA - Individuals with Disabilities Education Act.
- UNESCO. (2022) Singapore Inclusion – Education-Profiles.org
- Official Gazette of the Republic of the Philippines. (2022) Republic Act No. 11650
- Kuwana M. (2014) Barriers to accessing health care services for children with disabilities in Southern Africa: The case of Namibia [master's thesis]. [Oslo: Oslo and Akershus University College. 59p.
- Philippine Statistics Authority. (2018) Annual family income.
- Lasco G, Nuevo CEL, Nolasco MLP, Famaloan FRAN, Bundoc JR, Capili DIS, *et al.* (2021) "It's as if I'm the one suffering": Narratives of parents with children with disability in the Philippines. *Acta Medica Philippina.* DOI: <https://doi.org/10.47895/amp.vi0.658>
- Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter S, Russell D, *et al.* (2005) The health and well-being of caregivers of children with cerebral palsy. *Pediatrics.* 115:e626 DOI: 10.1542/peds.2004-1689
- Nobakht Z, Rassafiani M, Hosseini SA. (2018) A web-based caring training for caregivers of children with cerebral palsy: development and evaluation. *Iran J Child Neurol.* Autumn. 12(4):65-84.
- Bourke-Taylor H, Fiona J, Peat J. (2019) Healthy mothers healthy

- families workshop intervention: a preliminary investigation of healthy lifestyle changes for mothers of a child with disability. *Journal of Autism and Developmental Disorders*. 49(3). DOI: 10.007/210803-018-3789-1
44. Marron EM, Redolar-Ripoll D, Nieto R, Guillamon N, Hernandez E, Gomez B. (2013) Burden on caregivers of children with cerebral palsy: predictors and related factors. *Universitas Psychologica*. 12(3):767-77.
 45. Chiluba BC, Moyo G. (2017) Caring for a cerebral palsy child: a caregivers perspective at the University Teaching Hospital, Zambia. *BMC Research Notes*. 10:724. <https://doi.org/10.1186/s13104-017-3011-0>
 46. Philippine Health Insurance Corporation. (2016) Circular No. 2016-032. Guiding Principles For The Z Benefits For Children With Disabilities.
 47. Philippine Statistics Authority. (2020) Household population.
 48. Philippine Statistics Authority. (2020) Annual family income.
 49. Rezaie L, Kendi S. (2020) Exploration of the influential factors on adherence to occupational therapy in parents of children with cerebral palsy: A qualitative study. *Patient Prefer Adherence*. 2020;14:63-72.
 50. Halpern R, Gillard P, Pharm DG, *et al.* (2013) Adherence associated with oral medications in the treatment of spasticity. *PMR*. 5(9):747-56.
 51. Jimmy B, Jose J. (2011) Patient medication adherence: measures in daily practice. *Oman Med J*. 26(3):155-9. doi: 10.5001/omj.2011.38.
 52. Jing J, Sklar GE, Min Sen Oh, *et al.* (2008) Factors affecting therapeutic compliance: a review from the patient's perspective. *Ther Clin Risk Manag*. 4(1):269-286. Doi:10.2147/tcrm.s1458.
 53. Alshehri A, Bach C. (2014) Challenges of cerebral palsy management. ASEE 2014 Zone I Conference, University of Bridgeport, Bridgeport, CT, USA.