

**QUALITY OF LIFE AND STRESS OF PRIMARY CAREGIVERS IN
CHILDREN WITH CEREBRAL PALSY: A CROSS-SECTIONAL
STUDY**

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UTKAL UNIVERSITY Bhubaneswar, Odisha

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In Partial fulfilment of the requirements for the degree of

MASTER OF PHYSIOTHERAPY (M.P.T)

In

NEURO PHYSIOTHERAPY

Under the guidance of

Prof. JOSEPH OLIVER RAJ

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**ABHINAV BINDRA SPORTS MEDICINE & RESEARCH
INSTITUTE Bhubaneswar, Odisha**

2022-2024





DECLARATION BY THE CANDIDATE

I hereby declare that this dissertation entitled '**QUALITY OF LIFE AND STRESS OF PRIMARY CAREGIVERS IN CHILDREN WITH CEREBRAL PALSY: A CROSS-SECTIONAL STUDY**' is a bonafide and genuine research work carried out by me under the guidance of Prof. JOSEPH OLIVER RAJ, Dean and Co-guidance of Dr. Asma Parveen, Assistant Professor, Dept. of Neurosciences Abhinav Bindra Sports Medicine and Research Institute, Odisha

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LIST OF ABBREVIATIONS

1. **ABSMARI** - Abhinav Bindra Sports Medicine and Research Institute
2. **CP** – Cerebral Palsy
3. **QoL** – Quality of Life
4. **PCGs** – Primary Care Givers
5. **PSS**– Parental Stress Scale
6. **MKS**- Modified Kuppuswamy Scale
7. **GMFCS E & R**– Gross Motor Function Classification Scale Expanded and Revised
8. **SPSS** – Statistical Package for Social Science
9. **SD** – Standard Deviation

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ABSTRACT

QUALITY OF LIFE AND STRESS OF PRIMARY CAREGIVERS IN CHILDREN WITH CEREBRAL PALSY: A CROSS-SECTIONAL STUDY

Background: This study aimed to assess the quality of life and stress of primary caregivers of CP children and find correlations between their QoL and stress with the clinical profiles of CP children.

Methods: An observational cross-sectional study was conducted on 152 primary caregivers (mothers) of children with CP. The QoL and stress of the caregivers were assessed using the World Health Organization Quality of Life Instrument (WHOQOL-BREF - physical, psychological, social, and environmental domains) and the Parental Stress Scale (PSS) respectively. The child's gross motor function level was determined using the Gross Motor Functional Classification System-Expanded and Revised (GMFCS-ER). The correlation of stress with GMFCS-ER and WHO-QoL Bref of primary caregivers with GMFCS-ER in children was assessed. Also, the effect of the socioeconomic status of the study population on the Quality of life and stress of primary caregivers has been analyzed.

Results: The statistical analysis showed the severity of gross motor dysfunction in CP children had a great statistical significance on the primary caregivers' quality of life as well as on their stress.

Conclusions: Caregiving a child with CP causes a significant impact on the quality of life of primary caregivers with increasing severity of motor dysfunction as well as the parental stress of the mothers.

Key Words: Cerebral palsy, Primary caregiver, Stress, Quality of life

INTRODUCTION

Cerebral palsy (CP) is childhood's most common neurodevelopmental motor disorder, defined as a group of neurological disorders caused by a non-progressive lesion to the developing brain that occurs with prenatal, perinatal, or postnatal etiology. Worldwide, it is the leading cause of childhood disability [1], as globally published literature has reported that the range of CP is from 1.5 to 4 per 1000 live births. However, the prevalence range reported for India is higher, ranging from 2.08 to 3.88 per 1000 live births, making it one of the most common causes of disability in India [2].

Previously, the Persons with Disability (PwD) Act of India recognized disability in terms of visual, speech, hearing, locomotor, and mental disability. Recently, amendments in the act were done, and the Rights of Persons with Disabilities (RPwD) Act, 2016 now covers CP in the sub-classification of physical disability as a locomotor disability.[3]

Acc. to Percentage of de jure household population having a disability by type of disability, according to the residence, age, and sex, Odisha, 2019-21: The number of persons with locomotor disabilities is 0.8% of the total disabled persons, ranging from age 0 to 24 years in both urban and rural areas which is not sufficient enough data to provide the knowledge regarding the prevalence of CP child in our state.[4]

Although motor dysfunction is considered a hallmark of CP, these children also suffer from other problems such as epilepsy, chronic pain, disturbances of sensation, perception, cognition, communication, learning & behavior, speech, and visual impairment, and gastrointestinal problems . They also have several limitations in self-care functions such as feeding, dressing, bathing, toileting, mobility, and social participation. These limitations can result in long-term care requirements that far exceed the normal children's usual needs. [5,6]

In our Indian culture; primarily the mother acts as the primary caregiver of children, who facilitates children's interaction with their surroundings and their integration

into a wide range of contexts. A child needs caregivers who are confident in their ability to provide care and who do so regularly for them to grow up to be healthy adults.[7]

But when it comes to taking the burden of caregiving for a CP child, mothers not only have to help the child with daily activities, but they also need to pay close attention to their changing health conditions.

Therefore, they tend to perceive their health as unsatisfactory, with muscle pain, symptoms of depression, reduced quality of life, and stress which directly leads to changes in their lifestyle and a decline in their quality of life. [8,9]

Their burden has been defined as a multidimensional response to physical, emotional, psychological, and financial stressors that are associated with taking good care of the child with CP and fulfilling their specific needs.

They have a greater level of stress as a result of having to manage a multitude of shifting demands and challenges, which negatively impacts their social, mental, and physical well-being [10,11,12]

WHO defines the Quality of Life (QoL) as the Individual's perception of their position in a specific cultural, social & environmental context as well as concerning personal goals, expectations, standards, and interests which is a broad-ranging concept influenced in a complicated way by the person's physical well-being, mental state, individual opinions, social connections and their correlation to notable specifications of their environment [13]

The CP child's physical, emotional, and social health are intrinsically linked, so the care of children with cerebral palsy (CP) depends as much on the mothers' willingness as it does on the children's physical and emotional well-being, so they can overcome every obstacle involved in giving care. A mother's poor physical or mental health may prevent them from meeting these challenges, which could prevent the child from developing a higher level of function. [14]

With little to no support from family or the community; the mother, who is typically the primary caregiver, often bears the primary responsibility for raising such a child. In addition to trying to deal with the challenges and complexities brought on

by their children's illnesses, they also struggle to meet their own physical, psychological, and social needs [15].

The International Classification of Functioning, Disability, Health -Children & Youth version [WHO] states that because caregivers have a significant impact on their children's functioning, social environment, and overall health, the family system as a whole must be taken into account.

Since there is no literature available in Odisha addressing this issue, it is imperative to investigate the impact of raising a kid with CP on caregivers' quality of life and level of stress. Therefore, this study was conducted to assess the attitudes, environmental and physical well-being, and knowledge of parents of children with cerebral palsy and to emphasize the impact of cerebral palsy and disability on the caregivers.

NEED OF THE STUDY

Initiatives for community-based and family-centered care for disabled children must incorporate interventions that assist and maintain parents in their responsibilities as long-term caregivers if they are to be effective. Therefore, identifying those parents is essential to proactively offering the right services.

The caregiver's physical, emotional, and psychosocial well-being is crucial and should be regularly evaluated to improve the quality of life for children with cerebral palsy.

Our state Odisha; is the fastest-growing economy in India with an estimated gross state domestic product (GSDP) growth of 6.23% for the financial year 2021-22. But there is no availability of any literature describing the prevalence which implies the impact of raising a child with CP, which affects the current disease burden estimation and will further increase stress on family finances as well as the regional and national economy.

Therefore, to provide the optimum care and for the well-being of a child with such dysfunction, it is necessary to assess and evaluate the mother's physical, mental, and social well-being.

Aim of the study:

To evaluate the correlation between the severity of motor dysfunction of the CP child with the quality of life of primary caregivers and their parental stress.

OBJECTIVES OF THE STUDY

- ❑ To assess the Quality of Life of Primary caregivers with CP children by using the WHO Quality of Life Brief Questionnaire (WHO QoL BREF).
- ❑ To assess the stress of primary caregivers as parents by using the Parental Stress Scale (PSS).
- ❑ To assess the severity of motor dysfunction of CP children by using the Gross Motor Function Classification Scale (GMFCS - ER)
- ❑ To evaluate the correlation between GMFCS - ER and WHO - QoL Bref
- ❑ To evaluate the correlation between GMFCS - ER with PSS

Hypotheses:

- **Null Hypothesis**
 - H01: There will be no significant correlation between the QoL of the Primary caregiver with the clinical profile of the CP child.
 - H02: There will be no significant correlation between the Stress of the Primary caregiver with the clinical profile of the CP child.
- **Alternate Hypothesis**
 - H11: There will be a significant correlation between the QoL of the Primary caregiver with the clinical profile of the CP child.
 - H12: There will be a significant correlation between the Stress of the Primary caregiver with the clinical profile of the CP child.

REVIEW OF LITERATURE

- **Manasi S. Vaidya, Vijay K Dimple (2024)** in **Journal of Preventive Medicine Research & Reviews**: published a study '**Quality of Life of the Family Caregivers of Children with the Cerebral Palsy and its Determinants: A Study from India**' to assess the QoL and its determinants amongst family caregivers of children with CP that was conducted in a Tertiary Care Hospital in Yavatmal, Maharashtra, from March to May 2022, involving 126 participants. The study found a significant association of QoL with the age of the caregiver, residence, education, socio-economic class, total number of children, health insurance, and accessibility of services concluding that more than half of the study participants exhibited low overall, physical, social and environmental QoL, influenced by various determinants.
- **Jaya Shanker Tedla et al** in **Journal of Multidisciplinary Healthcare (2023)**: published a study on '**Caregiver's Quality of Life Among Children with Cerebral Palsy in the Kingdom of Saudi Arabia, and Various Influencing Factors: A Single Cohort Study**' to evaluate the quality of life among caregivers of children with cerebral palsy and to observe the effects of various demographic factors and affected child-related factors on caregivers' quality of life. 106 caregivers of children with cerebral palsy from the Asir region of Saudi Arabia were recruited for the study. They got that conclusion; a moderately significant correlation between total QOL in comparison with caregivers' educational level and mobility capacity, with R values of 0.54 ($p < 0.001$) and 0.62 ($p < 0.001$), respectively. Factors such as increased mobility and education of the affected child contributed to better total QOL scores.
- **Fang Liu et al (2023)** in the **Journal BMJ Open**: published a systemic review on '**Factors associated with caregiver burden among family caregivers of children with cerebral palsy**' to identify caregivers and children factors associated with the burden and concluded that it was most often associated with depressive feelings, worse life quality of the caregiver, and with more severe physical disability of the children.
- **Alice Namanja, Vincent Samuel Phiri (2022)** in **Malawi Medical Journal**: conducted a study on '**Quality of life of primary caregivers of**

children living with cerebral palsy at two clinics in Blantyre, Malawi' to determine QoL of 142 no. of PCGs of the children aged 2 to 18 years of age who were receiving rehabilitation in those centers from January to April 2019. The study established that PCGs possess poor QoL.

- **Vivek H Ramanandi, Yagna U Shukla (2022)** in the Journal **Bulletin of Faculty of Physical Therapy**: published a study on '**Socio-demographic & clinical profile of pediatric patients with cerebral palsy in Gujurat, India**'; a cross-sectional study conducted in various physiotherapy clinics, rehab centers and neurology clinics in Ahmedabad including 481 no. of children with CP for studying the socio-demographic and clinical profiles of cerebral palsy children in Gujurat.
- **Dania A. Kouther et al (2022)** in **Frontiers in Pediatrics**: published a literature; '**Factors influencing the mental health of caregivers of children with cerebral palsy**' a cross-sectional study conducted on 40 no. of caregivers to determine the different factors affecting the mental health of caregivers of children with cerebral palsy and to raise awareness among healthcare providers.
- **Swapnil P. Sonune, Anil K. Gaur et al (2021)** in the **Journal of Family Medicine and Primary Care**: conducted a study on '**Prevalence of depression and quality of life in primary caregiver of children with cerebral palsy**' an observational cross-sectional study was conducted on a total of 203 PCGs of children with CP to study the correlation of depression and QoL; concluding that caregiving causes a significant impact on the QoL with increasing severity of depression among the mothers of children with CP.
- **Kelvin Ying, Hans Rosenberg et al (2021)**, in the **Journal of International Journal of Environmental Research and Public Health**: conducted a study on '**Health-Related Quality of Life and Family Functioning of Primary Caregivers of Children with Cerebral Palsy in Malaysia**'; a cross-sectional study involved a total of 159 primary caregivers of children with CP to examine the overall impact of caregiving for children with CP on the primary caregivers' health-related quality of life (HRQOL) and family functioning, and to identify potential factors associated with it.
- **Alanoud Akram Aman et al (2021)** in the Journal **Pharmacophore**: Conducted a study '**A Cross-Sectional Study to Evaluate The Quality Of Life Of Caregivers For Children With Cerebral Palsy**'; a cross-sectional

study was conducted from June 2017 to July 2018 to evaluate the QoL of 129 no of caregivers of 4-18 years old cerebral palsy children using a self-structured questionnaire concluding the Quality of Life of parents of children with CP was influenced in all aspects.

- **Malek Amini et al (2020)** in the **International Journal of Nursing Practice**: published a study on '**Factors Associated with Quality of Life among Mothers of children with Cerebral palsy**'; a cross-sectional study was conducted including 203 mothers of children with cerebral palsy to identify the factors related to the QOL. The results indicated that depression, the burden of care, fatigue, and the type of cerebral palsy significantly affect and lower the QOL in these mothers.
- **Meen Hye Lee et al (2019)** in the **Journal of Paediatric Nursing**: conducted a cross-sectional study in Korea with 180 sample size on '**Determinants of Health-related Quality of Life among Mothers of Children with Cerebral Palsy**'; to identify the determinants affecting Health-related Quality Of Life among mothers of CP Children. The study revealed that physical HRQOL > Mental HRQOL. HRQOL was determined by a no. of variables like child characteristics, maternal characteristics, and environmental factors.
- **Alma Glinac, Lejla Matovict et al. (2017)** in the European Journal **Acta Clinica Croatica**: published a study on '**Quality Of Life In Mothers Of Children with Cerebral Palsy**'; to investigate whether there was any difference in the QoL between mothers of CP children and mothers of healthy children. As well as whether the QoL of mother's depend on their education, child's mobility and functional status. Sample size =141 ,control group consisting 70 mothers of normal children. The study showed that mothers of children with CP had poorer QoL than mothers of healthy children . In relation to mobility of the child ; the QOL of mother's was worse for CP children with no social functioning and dependency as compared to CP children with independent mobility.

METHODOLOGY

- ☐ Study design - a cross-sectional: descriptive study
- ☐ Study population - Primary caregivers of Patients with CP, CP children
- ☐ Study sample - Purposive sample
- ☐ Sample size -152
- ☐ Study setting -NGOs, Rehabilitation Centers, Pediatric OPDs in Hospitals, Khordha & Cuttack
- ☐ Study duration - 6 months

Selection criteria:

☐ **Inclusion criteria:**

- ✓ Children diagnosed with Cerebral palsy
- ✓ CP Child Age – 5 to 18 years & their primary caregivers
- ✓ Primary caregiver – providing the majority of health care for child's ADLs in their home for at least 1 year or more
- ✓ Children coming to those study mentioned above settings with their Primary caregivers and are willing to participate

☐ **Exclusion criteria:**

- ✓ Child diagnosed with other neurological conditions other than Cerebral palsy.
- ✓ Primary caregivers who had a long history of diabetes, hypertension, or any cardio-pulmonary-renal illness.
- ✓ Primary caregivers suffering from psychological and cognitive-behavioral illness who cannot understand and co-operate for the study.
- ✓ Primary caregiver with another child below 2 years of age or another child with special needs.

Outcome Measures :

1. Socio-economic and demographical Data: It encompasses various factors related to individuals' social and demographic context. These include age, gender, education level, occupation, income, marital status, and more. To

assess the socioeconomic status of the study population the Modified Kuppaswamy Scale (MKS) was Used.

2. WHO-QoL – BREF :

This scale was developed by The World Health Organization to measure Quality of Life.

It contains 26 items with 5 major domains -

- a) General Health (2 items)
- b) Physical Health (7 items)
- c) Psychological Health (6 items)
- d) Social Relationship (3 items)
- e) Environment (8 items)

The total score ranges from a minimum of 27 to a maximum of 135.

Cronbach's alpha = 0.81

3. Parental Stress Scale :

It is an 18-item questionnaire assessing parents' feelings about their parenting role.

It explores both positive aspects (e.g. emotional benefits, personal development) and negative aspects of parenthood (e.g. demands on resources, feelings of stress).

Overall possible scores on the scale range from 18 – 90. The higher the score, the higher the measured level of Parental stress

To compute the parental stress score, items 1, 2, 5, 6, 7, 8, 17, and 18 should be reverse scored as follows: (1=5) (2=4) (3=3) (4=2) (5=1)

Cronbach's alpha = 0.84

4. Gross Motor Function Classification System – E & R :

The functional level of a child with CP will be determined by using the GMFCS.

It is a reliable & valid 5-level classification system that classifies the severity of gross motor function of CP child by their age-specific gross motor activities.

It describes the major functional characteristics of CP child within the following age : Between 4 years to 6 years, 6 years to 12 years and 12 years to 18 years .

The function is divided into 5 levels: Level I to Level V

For Intra-rater reliability – ICC = 0.98 , For Inter-rater reliability – ICC = 0.97

PROCEDURE

Ethical Clearance was taken from the Institutional Ethical Committee

Subjects were selected on the basis of Inclusion & Exclusion Criteria

Informed consent forms were obtained from all the subjects

Procedure was explained to the study population

Socio-economic and demographic data of both children & Primary caregivers were noted down

To assess QOL the WHO QOL-Bref and for stress the Parental Stress Scale was filled up by the subjects

All the data were stored in an Excel sheet

Data interpretation and analysis was conducted using SPSS software

Ethical Considerations:

The Institutional Ethical Committee (IEC) evaluated and approved the current study. Information was provided on the purpose of the research, identity confidentiality, the voluntary nature of participation, and the guarantee of the right to refuse the involvement without any form of retaliation, in addition to other aspects relevant to the research, as well as clarification of doubts about the study.

Participants :

152 primary caregivers of children with CP from 5 to 18 years participated in this study based on inclusion and exclusion criteria. They understood and completed the questionnaire. The diagnosis of CP in children was based on the clinical assessment. Everyone who participated in the survey was informed about the study, and their informed consent was obtained before enrolling them in the study

Data Collection :

The demographic details such as the PCG's age, child's age and gender, mother's education, any related health condition, and socioeconomic data were noted. After examining the child, the type of CP (spasticity, ataxia, dystonia, athetosis, or mixed) and the child's motor function level were noted. The functional level was determined using the Gross Motor Functional Classification System- Expanded and Revised (GMFCS-ER), the quality of life of PCGs was assessed by WHO QOL-BREF Odia version, and for the assessment of stress as a parent was obtained using Parental Stress Scale (PSS).

Statistical Analysis :

The categorical variables were presented in the form of numbers and percentages (%). On the other hand, the continuous variables' presentation was done as mean $\pm$ SD values. The data normality was checked by using the Kolmogorov–Smirnov test. In cases where the data was abnormal, we used nonparametric tests. The Spearman's rank correlation coefficient was used to correlate the WHO QoL Bref with GMFCS-ER grading and the Parental Stress Scale for stress with GMFCS-ER. The univariate linear regression was used to find out factors affecting the QoL. The final analysis was done with the use of the Statistical Package for Social Sciences (SPSS) software ver 22.0.

RESULTS

The mean age of the studied Primary caregivers was 33.36 $\pm$ 5.35 years and children with CP was 8.32 $\pm$ 2.84 years with 36.18% (n = 55) females and 63.81% (n = 97) males. Shows in Table 1.1

Among the participants, 19.07% (n=29) were primary educated, 50.65% (n = 81) were secondary educated, 317.76% (n = 27) were intermediate and 12.5% (n = 19) graduate or post-graduate. Table 2.1 shows the demographic characteristics of the study population.

AGE	MEAN	SD
CP Children	8.32	2.84
PRIMARY CAREGIVERS	33.36	5.35

Table 1.1 Mean Age Analysis

Among the Primary caregivers, 63.8% (n=97) of mothers chiefly complained of low back pain during the assessment. Table 2.2 shows the clinical profiles of the study population.

The type of CP was spastic in most children i.e. 54.6%, followed by 13.1% hemiparesis, mixed (10.52%), and dystonic type 8.7%. The other types included ataxic (3.28%), athetoid (5.26%), and flaccid/hypotonic types (4.6%).

The GMFCS-ER grading showed that 8.6% of the children were in level 1, 28.28% were in level 2, 29% were in level 3, 23.68% were in level 4 and 10.52% were in level 5.[Table 2.2]

As per the Parental Stress Scale, the mothers' mean stress score was 59.2 $\pm$ 8.4.

As per the WHOQOL-BREF, the mean $\pm$ SD score of the physical domain was 73.03 $\pm$ 9.9, the psychological domain was 57.72 $\pm$ 14.8, the social relationships was 66.2 $\pm$ 12.8 and the environmental domain was 73.51 $\pm$ 16.42.[Table 1.2]

WHO-QOL Bref Domains	MEAN	SD
PHYSICAL (D1)	73.03	9.9
PSYCHOLOGICAL (D2)	57.72	14.8
SOCIAL RELATIONSHIP (D3)	66.2	12.8
ENVIRONMENTAL (D4)	33.36	5.35
PARENTAL STRESS SCALE	59.26	8.4

Table 1.2 Mean Score of the Scales

SOCIODEMOGRAPHIC PARAMETERS	SUBCATEGORIES	FREQUENCY	PERCENTAGE
Distribution Of Age OF PCGs	20-29yrs	40	26.31
	30-39yrs	88	57.89
	40-49yrs	23	15.13
	50yrs and more	1	0.6
Distribution Of Age Of CP Children	5-8 yrs	95	62.5
	9-11yrs	33	21.7
	12-14yrs	17	11.18
	15-18yrs	7	4.6
Marital Status Of PCGs	Married	137	90.13
	Separated/Divorced	4	2.6
	Widowed	1	0.6
FAMILY INCOME (per annum in rupees)	<50,000	9	5.9
	50 K to 1 Lakh	37	24.34
	1 Lakh to 3 Lakhs	91	59.86
	>3 Lakhs	15	9.8
PCG'S EDUCATION	Primary	29	19.07
	Secondary	77	50.65
	Intermediate	27	17.76
	Graduate/Post-graduate	19	12.5
CP Child's Education	School going	24	15.7
	Home tuition	81	53.28
	No Education	47	30.92
Occupation	Employed	13	8.5
	Housemakers	139	91.44
Total No. Of Children	1	137	90.13
	2	10	6.5
	3	1	0.6
Socio-economic Grades(MKS)	I	20	13.15
	II	73	48.02
	III	37	24.34
	IV	21	13.81
	V	1	0.6

Table 2.1 Demographics Characteristics of Study Population

The association between GMFCS-ER with WHO-QOL Bref domains scores showed a significant decreasing trend with increasing motor dysfunction of the child; statistical association for physical ($r = -0.664$, $P = 0.000$), psychological domains ($r = -0.662$, $P = 0.000$) showed a moderate to strong significance than the other 2 domains that was, social relationship domains ($r = -0.239$, $p = 0.003$), and environmental domains ($r = -0.107$, $p = 0.1$). The Modified Kuppaswamy Scale showed a great statistically significant negative correlation only for

the psychological domain ($r = -0.510$, $P = 0.000$), and environmental domain ($r = -0.927$, $p = 0.000$) . [Table 3.1]

CLINICAL PROFILES	SUBCATEGORIES	FREQUENCY	PERCENTAGE
GMFCS LEVELS OF CP	GMFCS I	13	8.55
	GMFCS II	43	28.28
	GMFCS III	44	28.94
	GMFCS IV	36	23.68
	GMFCS V	16	10.5
TYPES OF CP	SPASTIC	83	54.6
	DYSTONIC	13	8.5
	ATAXIC	5	3.2
	ATHETOID	8	5.2
	MIXED	16	10.5
	HYPOTONIC	7	4.6
PCGs with LBP	Present	97	63.8
	Absent/Mild	55	36.1

Table 2.2 Clinical Profiles of Study Population

VARIABLES	PHYSICAL(D1)	PSYCHOLOGICA(D2)	SOCIAL RELATIONSHIPS(D3)	ENVIRONMENTAL(D4)
GMFCS-ER Grading				
Correlation coefficient	-0.664	-0.662	-0.239	-0.107
p**	0	0	0.003	0.01
Modified Kuppaswamy Scale				
Correlation coefficient	-0.065	-0.51	-0.46	-0.927
p**	0.43	0	0	0

**significant at the 0.01 level (Spearman's rank correlation coefficient)

Table 3.1: Correlation of Quality of Life domains, motor dysfunction in CP child and MKS Grading

The association between the Parental stress scale with the GMFCS- ER of CP children showed a moderate to strong statistical association ($r = 0.665$, $p = 0.000$) where the socioeconomic status of the primary caregivers showed a positive statistical association ($r = 0.615$, $p = 0.000$) on the stress of primary caregivers. [Table 3.2]

VARIABLES	PARENTAL STRESS SCALE
GMFCS-ER Grading	
Correlation coefficient	0.665
p**	0
Modified Kuppuswamy Grading	
Correlation coefficient	0.615
p**	0

**significant at the 0.01 level (Spearman's rank correlation coefficient)

Table 3.2: Correlation of Parental Stress Scale with GMFCS-ER of CP child and MKS Grading

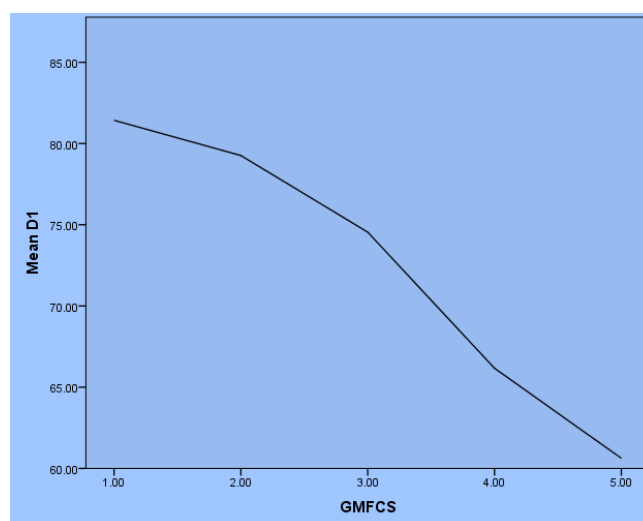


Figure 1.1: Correlation of GMFCS grading with Physical Domain (D1)

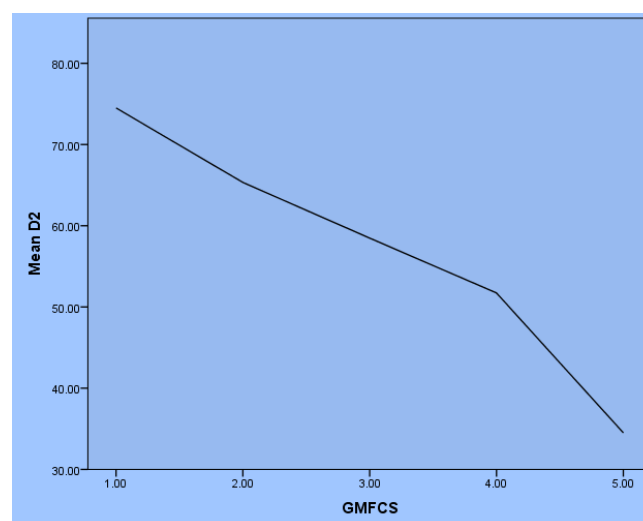


Figure 1.2: Correlation of GMFCS grading with Psychological Domain (D2)

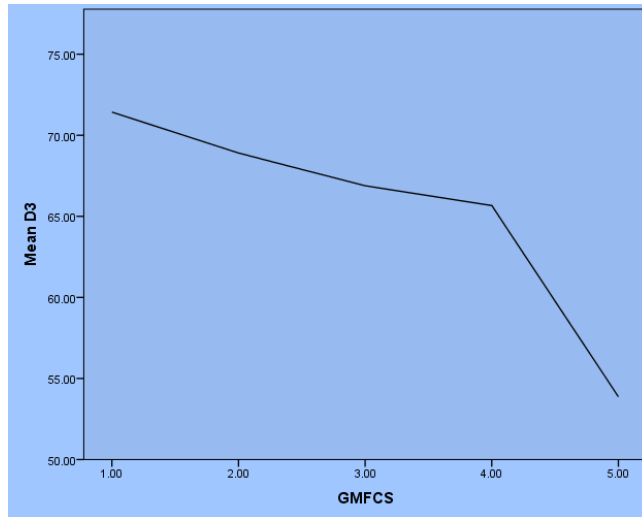


Figure 1.3: Correlation of GMFCS grading with Social Relationship (D3)

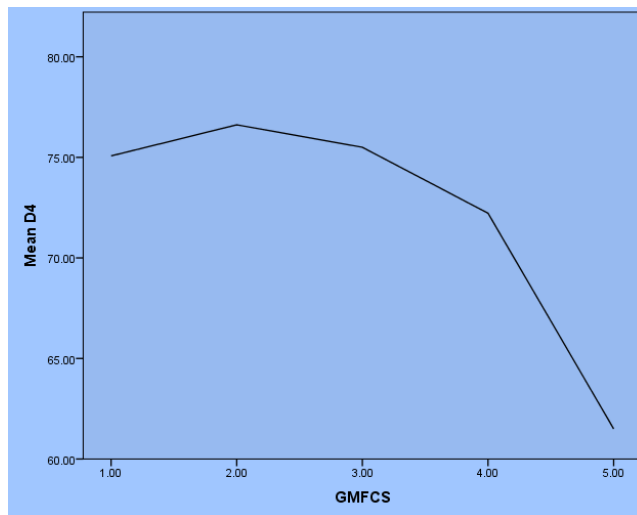


Figure 1.4: Correlation of GMFCS grading with Environmental domain (D4)

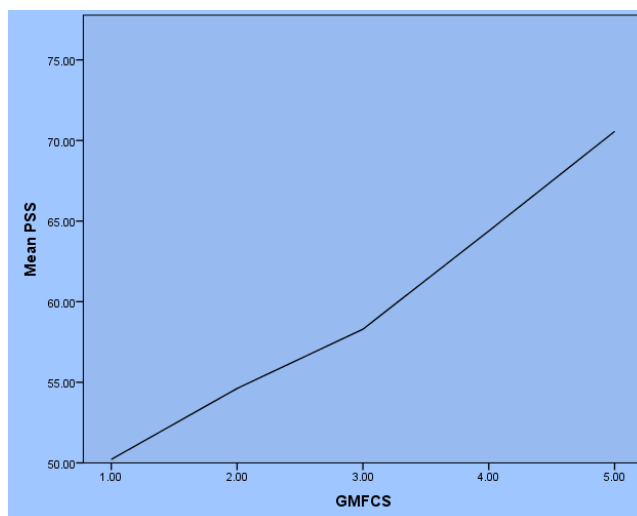


Figure 2.1: Correlation of GMFCS grading with Parental Stress Scale

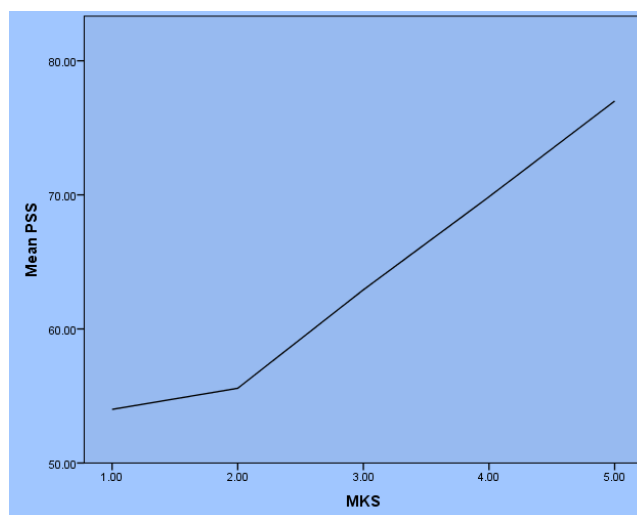


Figure 2.2: Correlation of Modified Kuppuswamy Scale (MKS) with Parental Stress Scale

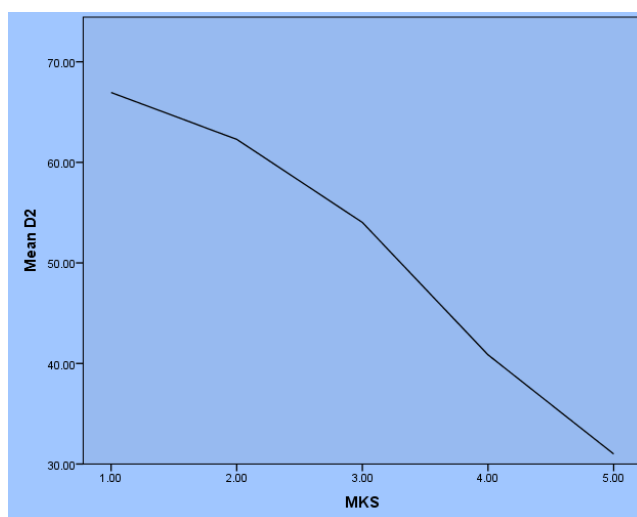


Figure 3.1: Correlation of Modified Kuppuswamy Scale with WHO-QOL Bref -Psychological Domain (D2)

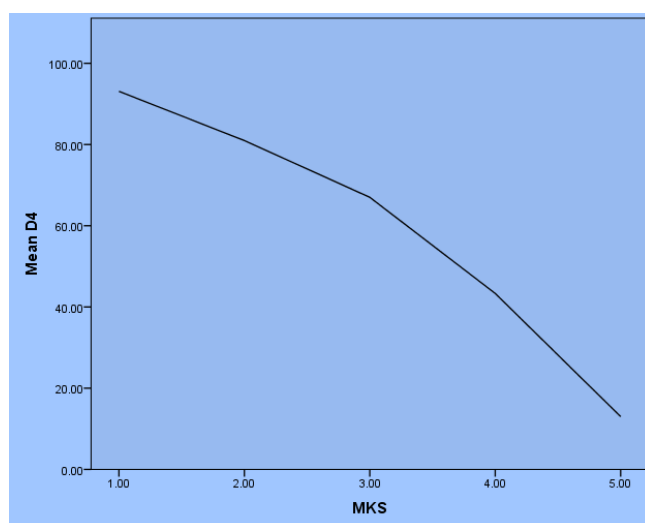


Figure 3.2: Correlation of Modified Kuppuswamy Scale with WHO-QOL Bref Environmental Domain (D4)

DISCUSSION

The present study investigated the correlation of gross motor dysfunction of a CP child with the Quality of life of the primary caregivers as well as with their stress as a parent. Caring for children with CP is a very stressful and physically challenging task. Primary caregivers of children with CP were under higher pressure than caregivers of healthy children. This level of stress is clinically significant and requires support and intervention from professional services. [16,17]

Byrne et al.[18] found poor psychological and physical health in CP caregivers compared to the average population; however, they found no relation between mental health with the functional level of CP children. However, this study reveals a significant correlation between parental stress and the psychological domain of WHO-QOL Bref with the functional level of CP children.

According to the results of this study, the caregiver's stress increases in tandem with the CP child's functional limitations. Maybe the explanation for relevance in our situation is the deeply rooted societal beliefs in Indian civilization that mothers are the only ones accountable for their children's growth.

A study conducted in India by Sardana R et al.[19] found that family activities, leisure time, and social interactions are disrupted for caregivers of children with cerebral palsy (CP). In this demographic, low self-esteem might result from thoughts of self-blame and feelings of guilt. CP children belong to low-income families and lack social support; causing the primary caregiver to feel alone and rejected by society causing a greater impact on the psychological and social relationship domain of the primary caregivers.

The QoL was also significantly affected by the functional level of the CP child, primarily in physical and psychological domains. There was no discernible significance in the environmental and social domains.

When the QoL domains; particularly the psychological and environmental domains and socioeconomic status of the primary caregivers were compared in this study, it became clear that it has a great influence, indicating a detrimental effect on the QoL of primary caregivers. Sarkar *et al.* [20] reported that the low socio-economic

status of most of the families contributed to a further decrease in the QoL of the primary caregivers.

The primary caregivers of CP children have responsibilities such as their body care, assisting the child in mobility, toileting, dressing, etc; and performing home exercises and activities that often require lifting and carrying the child. According to this study, 63.8% of mothers of children with CP reported having severe to moderate low back pain. The number of children, the age of the CP child, and the child's functional level may be the independent risk factors in the musculoskeletal system pain of these primary caregivers.

The mother's impacted quality of life and stress as a parent, as well as the CP child's motor dysfunctions, were evaluated in this study, which gave it merit. In this case, it is important to emphasize that even if the mother provides the extra care needed for children with cerebral palsy (CP), doing so may put additional strain on her health and ultimately be harmful to both her and the child. These might make the mother feel worse or lessen her affection for the child, which would ruin the family dynamic and put more strain on the other family members.[21]

The study reveals that primary care of a CP child can become very stressful as it increases the physical, and psychological burden for mothers, and result in depression and a lower quality of life. So while treating a child with cerebral palsy, it is important to consider this factor to promote the patient's and family members' general recovery from the illness. Therefore, it is the responsibility of the primary care physician to provide counseling to the family of the children with CP regarding their care.

To enhance their well-being, it recommends legislative actions. These include improving healthcare facilities, especially in remote areas, financial help schemes, & social support programs. Programs for raising awareness and educating the public may help people better understand CP, its treatment choices, and its resources. Policies should adjust support to reflect the variety of family arrangements that care for people with cerebral palsy.[22]

CONCLUSION

In an Indian setting, the mother of the child, or the primary caregiver, must be involved for the dysfunction associated with a CP Child to be effectively managed in home-based care. For mothers and their CP-affected children, the current study offers fresh insights that could inform the creation of a parenting guide.

It is critically important to consider the caregiver's mental health and provide the mother with multidisciplinary medical, psychological, and social support. It follows that improving mothers' quality of life and the care they receive can be achieved by concentrating on the burden of care, stress, and exhaustion and figuring out realistic strategies to lessen their effects to enhance both the child's and the primary caregivers' prospects of recovery.

Therefore, the goal of interventions should be to provide the primary caregivers with the knowledge, skills, and tools necessary to effectively manage the caregiving load that results in the improvement of the health and recuperation of CP children.

LIMITATIONS

The present study should be considered within the context of its limitations. First, the sample size was small and not representative of the overall population. Second, the use of purposive sampling limits the external validity and generalizability of the results. Third, the majority of participants were from urban regions, which could help with future studies on primary caregivers of children with cerebral palsy in rural locations.

In spite of these drawbacks, the present study's findings suggest that contextual elements of the study should be taken into account when evaluating the well-being of primary caregivers.

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ANNEXURES.1

CONSENT FORM

INFORMED CONSENT

Study Title : **QUALITY OF LIFE & STRESS OF PRIMARY CAREGIVER'S WITH CEREBRAL PALSY CHILDREN : A CROSS SECTIONAL STUDY**

Study Protocol ID: ABS-IEC-2023-PHY-025 [IEC Approved]

Primary Care giver's Name: _____

Child's Name: _____

Age/Gender: _____

Age/Gender: _____

Address: _____

Qualification: _____

Occupation: Service/Housewife/Others (Please tick as appropriate)

- I. I have been informed well about the above mentioned study by Mlss. Sumitra Mohanty; pursuing her MPT (Neuro) in Abhinav Bindra Sports Medicine And Research Institute (ABSMARI) ,conducting this study under the guidance of Dr. Joseph Oliver Raj ,Dean, ABSMARI (BBSR).
- II. I understand that my and my child's participation in this study is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
- III. I understand that the information produced by the study will become a part of the institute's record and will be utilized, as per confidentiality regulations of the institute. I am also aware that the data might be used for medical literature and teaching purposes, but all the personal details will be kept confidential.
- IV. I am well informed to ask as many questions as I can to MS. Sumitra Mohanty either during the study or later. I wish to discuss my and my child's participation and concerns regarding this study with a person not directly involved .
- V. I agree for my as well as my child's participation in the above study.
- VI. Signature (or Thumb impression) of the Subject/Legally Acceptable Representative: _____

Date: ____/____/____

Signatory 's Name: _____

Signature of the Investigator: _ _____

Date : _____

ANNEXURES.2

ASSESSMENT FORM

ASSESSMENT FORM :

NAME:

AGE/GENDER:

DATE:

OCCUPATION:

DOMINANCE:

CONTACT NO.

ADDRESS:

SUBJECTIVE EXAMINATION:

CHIEF COMPLAINT:

HISTORY OF PRESENT ILLNESS (HOPI):

PAST HISTORY:

PERSONAL HISTORY:

FAMILY HISTORY:

ENVIRONMENTAL HISTORY:

OCCUPATIONAL HISTORY:

SOCIOECONOMIC HISTORY:

OBJECTIVE ASSESSMENT:

ON OBSERVATION:

BODY BUILT:

GAIT:

POSTURE:

ON EXAMINATION: FOR CEREBRAL PALSY Child

1. Gross Motor Classification System E & R -

ANNEXURES.3

ETHICAL COMMITTEE CLEARANCE CERTIFICATE



ABSMARI ETHICS COMMITTEE

ABHINAV BINDRA SPORTS MEDICINE AND RESEARCH INSTITUTE,
BHUBANESWAR, ODISHA

Prof. (Dr.) E. Venkata Rao
Chairperson

Mr. Chinmaya Kumar Patra
Member Secretary

Ref. No. ABSMARI/IEC/2023/067

Date: 16/10/2023

APPROVAL LETTER

APPENDIX- VIII

To,

Sumitra Mohanty
ABSMARI
273, PAHAL, BHUBANEWAR-752101

Protocol Title: Quality of Life and Psychosocial Stress of Primary Caregiver's in Children with Cerebral Palsy : A Cross-Sectional Study.

Protocol ID.: ABS-IEC-2023-PHY-025

Subject: Approval for the conduct of the above referenced study

Dear Mr./Ms./Dr **Sumitra Mohanty**

With reference to your Submission letter dated 12/08/2023 the ABSMARI IEC has of the Ethics reviewed and discussed your application for conduct of clinical trial on dated 02/09/2023 (Sat Day).

The following documents were reviewed and discussed

S.N.	Documents	Document (Version/Date)
1	IEC Application Form	08-08-2023
2	Informed Consent Form	08-08-2023
3	Undertaking form PI	08-08-2023
4	CRF	08-08-2023
5	COI from the Investigators	08-08-2023

The following members were present at meeting held on 02-09-2023

S.N.	Name of the Member	Designation & Qualification	Representation as per NDCT 2019	Gender (M/F)	Affiliation with the Institution (Y/N)
1	Prof. Dr. E. Venkata Rao	Professor (MBBS, MD, Dept. of Community Med.) IMS & Sum Hospital, BBSR	Chair Person	M	N
2	Dr. Satyajit Mohanty	Director-Medicare Hospital, BBSR	Basic Medical Scientist	M	N
3	Dr. Ashok Singh Chouhan	PhD, Pharmacology, Assoc. Prof. Dept. of Pharmacology, Hi-Tech Medical College & Hospital, BBSR	Basic Medical Scientist	M	N



1

Uikal Signature, Plot No.-273,
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iec@absmari.com

**ABSMARI**

ABSMARI ETHICS COMMITTEE

ABHINAV BINDRA SPORTS MEDICINE AND RESEARCH INSTITUTE,
BHUBANESWAR, ODISHA

Prof. (Dr.) E. Venkata Rao
Chairperson

Mr. Chinmaya Kumar Patra
Member Secretary

Ref. No. ABSMARI/IEC/2023/067

Date: 16/10/2023

MEMBERS

Dr. Smaraki Mohanty,
Clinician

Dr. Satyajit Mohanty,
Basic Medical Scientist

Dr. Ashok Singh Chouhan
Basic Medical Scientist

Mr. Shib Shankar Mohanty
Legal Expert

Ms. Annie Hans,
Social Scientist

Ms. Subhashree Samal,
Lay Person

Mr. Deepak Ku. Pradhan,
Scientific Member

IEC-SECRETARIAT

Mr. Gouranga Ku. Padhy
Mr. Susant Ku. Raychudamani

S.N.	Name of the Member	Designation & Qualification	Representation as per NDCT 2019	Gender (M/F)	Affiliation with the Institution (Y/N)
4	Dr. Smaraki Mohanty	Asst. Prof-IMS & Sum Hospital/MBBS, MD (Community Med)	Clinician	F	N
5	Mr. Chinmaya Kumar Patra	Principal-ABSMARI, MPT	Member Secretary	M	Y
6	Mr. Shiba Sankar Mohanty	Junior Counsel-Lt, Ramachandra Sarangi's Chamber / BA LLB	Legal Expert	M	N
7	Ms. Annie Hans	Disability Inclusive Development Co-Ordinator in Humanity and Inclusion (India/Nepal/Srilanka). /MA in Social Work	Social Scientist	F	N
8	Ms. Subhashree Samal	Ret. Reader-Pol Sc.	Lay Person	F	N
9	Mr. Deepak Kumar Pradhan	Asst. Prof-ABSMARI, MPT	Scientific Member	M	Y

This is to confirm that only members who are independent of the Investigator and the Sponsor of the trial have voted/ provided opinion on the trial.

This Committee approves the documents and the conduct for the trial in the presented form with necessary recommendation.

The ABSMARI IEC must be informed about the progress of the study, any SAE occurring in the course of the study, any changes in the protocol and patient information/informed consent and requests to be provided a copy of the final report.

The ABSMARI IEC follows procedures that are in compliance with the requirements of ICH (International Conference on Harmonization) guidance related to GCP (Good Clinical Practice) and applicable Indian regulations.



Yours sincerely,

Mr. Chinmaya Kumar Patra
Member Secretary

ABSMARI Ethics Committee
Pahal, Bhubaneswar
Member Secretary
ABSMARI ETHICS COMMITTEE

2



**Utkal Signature, Plot No.-273,
Ground Floor, Pahal, Bhubaneswar-752101**

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ANNEXURES.4 - MASTER CHART

PCGs SL No.	Age	PSS	D1	D2	D3	D4	MKS	CP Age	GMFCS
1	38	65	63	63	81	88	I	12	IV
2	27	55	63	63	50	81	III	5	III
3	30	60	63	44	69	69	III	9	III
4	39	53	69	63	75	81	II	11	II
5	35	56	81	69	75	94	I	8	III
6	42	70	56	44	56	44	IV	9	IV
7	42	54	75	50	56	75	II	16	II
8	28	56	75	75	69	81	II	6	III
9	32	72	56	31	56	38	IV	15	V
10	38	66	63	44	69	81	II	11	IV
11	35	65	63	44	69	63	III	9	IV
12	35	61	69	56	75	94	I	11	V
13	40	69	56	38	44	81	II	16	V
14	28	56	81	44	50	81	II	5	III
15	28	59	81	69	69	88	I	6	IV
16	25	55	81	63	56	75	II	6	III
17	27	48	81	56	69	88	II	6	II
18	50	52	56	63	69	81	II	5	III
19	35	76	50	25	0	13	IV	16	V
20	37	71	56	31	50	63	III	13	V
21	30	62	63	50	69	81	II	13	IV
22	32	73	69	31	44	38	IV	6	V
23	27	65	63	38	50	88	II	8	V
24	24	67	63	38	50	69	III	13	IV
25	35	50	81	63	81	81	II	7	III
26	43	68	56	31	56	75	III	11	V
27	20	50	69	69	56	88	II	7	III
28	33	60	63	44	44	88	II	10	IV
29	28	61	63	56	50	88	II	6	III
30	32	60	56	63	81	94	I	8	IV
31	32	53	63	56	88	88	II	6	III
32	30	56	56	69	75	94	I	6	IV
33	31	61	69	63	75	69	III	7	IV
34	30	56	75	56	69	81	II	7	III
35	32	69	56	44	50	81	IV	8	IV
36	28	51	75	69	69	69	III	6	II
37	28	64	56	44	56	81	II	9	V
38	37	43	63	50	44	88	II	9	II
39	37	66	56	38	81	81	II	12	V
40	31	54	56	44	56	81	II	11	III
41	34	65	63	38	56	75	III	10	IV
42	42	45	69	69	81	81	II	13	II
43	31	48	69	75	81	94	I	6	III
44	25	51	88	69	81	63	III	5	I
45	27	49	88	69	81	63	III	5	II
46	39	62	69	56	75	44	IV	7	I
47	30	57	81	75	69	69	III	10	I
48	35	48	69	75	75	81	II	8	I
49	31	50	81	50	75	75	II	6	III
50	26	49	88	81	81	88	I	7	II
51	42	57	63	50	56	69	III	13	II
52	37	63	69	56	75	75	II	12	II
53	28	55	69	63	56	94	I	6	III
54	24	59	75	44	75	75	III	5	III
55	49	69	69	69	75	75	II	11	II
56	27	62	63	56	44	81	II	6	IV
57	33	44	69	69	75	81	II	6	I
58	24	52	81	56	69	88	II	5	III
59	32	63	75	44	75	69	III	6	II
60	38	61	50	56	69	94	I	8	IV
61	29	54	69	75	69	81	II	8	III
62	33	58	69	44	75	81	II	7	II
63	42	60	69	75	69	94	I	13	II
64	28	66	63	56	69	69	III	7	IV
65	42	42	69	69	75	88	II	13	II
66	30	58	63	50	69	94	I	8	IV
67	35	62	81	44	56	50	IV	6	II
68	40	57	69	63	75	88	II	7	III
69	39	42	63	63	56	88	II	16	II
70	28	64	81	75	69	94	I	7	II
71	35	60	75	56	56	69	III	7	II
72	43	73	56	44	75	44	IV	11	IV
73	23	53	81	63	69	88	II	6	II
74	33	58	81	69	56	75	III	8	II
75	28	60	88	56	81	88	II	6	II
76	32	71	75	38	56	44	IV	8	IV
77	32	63	31	33	33	33	V	3	V
78	30	74	69	38	50	44	IV	7	IV
79	31	49	81	81	75	81	II	6	I
80	35	75	56	56	69	69	III	6	II
81	32	59	69	63	75	88	II	8	IV
82	28	61	75	56	81	94	I	7	IV
83	28	62	81	56	56	50	IV	6	II
84	37	72	56	38	75	81	II	12	V
85	37	58	81	63	75	81	II	15	II
86	31	67	81	56	75	50	IV	8	III
87	34	65	88	56	81	81	II	8	II
88	42	70	69	31	56	63	III	14	III
89	31	61	81	63	56	75	III	5	II
90	32	49	88	81	75	81	II	6	I
91	27	50	88	81	75	81	II	5	III
92	39	57	81	63	81	94	I	8	III
93	30	60	88	63	75	88	II	6	II
94	35	65	81	56	75	75	II	6	III
95	31	57	88	81	69	81	II	5	II
96	26	77	75	44	56	44	IV	5	IV
97	42	70	69	50	69	63	III	8	IV
98	37	59	81	63	75	81	II	5	II
99	28	67	81	44	50	50	IV	6	III
100	24	52	88	75	69	81	II	6	II
101	31	75	44	44	69	69	III	8	IV
102	27	64	81	63	75	81	II	6	IV
103	33	71	69	50	56	69	III	9	V
104	34	54	81	88	75	81	II	7	II
105	32	61	81	69	75	81	II	7	III
106	38	63	88	63	50	69	III	9	II
107	29	48	88	81	69	94	I	5	I
108	31	51	63	63	75	75	II	6	II
109	42	58	81	63	75	69	III	11	II
110	28	64	81	56	81	63	III	7	III
111	42	51	75	63	75	81	II	9	III
112	30	60	81	56	56	63	IV	6	I
113	35	64	81	56	75	75	III	6	II
114	40	54	75	81	75	81	II	8	III
115	39	56	81	75	56	56	III	8	III
116	28	48	88	81	81	69	II	6	I
117	42	60	69	56	81	94	I	9	IV
118	30	65	81	44	44	56	IV	9	III
119	50	50	81	75	75	75	II	11	II
120	40	58	69	69	69	75	II	15	III
121	39	74	63	31	69	31	IV	12	IV
122	28	48	88	81	75	75	II	7	II
123	35	66	63	56	50	63	III	10	IV
124	43	69	81	69	69	56	III	12	II
125	29	53	88	75	56	81	II	6	I
126	38	59	75	56	81	75	II	10	IV
127	28	42	81	81	69	94	I	5	II
128	32	54	75	69	75	81	II	6	III
129	35	81	69	81	75	81	II	9	IV
130	30	48	88	81	50	88	II	5	I
131	31	70	81	44	44	44	IV	5	III
132	30	69	81	44	69	69	III	5	III
133	32	61	69	56	69	81	II	6	IV
134	28	68	69	44	44	38	IV	7	IV
135	34	59	75	81	81	75	II	11	III
136	37	64	81	63	56	63	III	13	II
137	39	61	81	63	69	63	III	11	II
138	31	67	81	56	50	63	III	8	III
139	34	58	63	63	75	75	II	9	IV
140	42	43	81	75	75	42	II	10	II
141	31	47	81	69	94	75	II	8	II
142	27	42	81	75	94	94	I	6	II
143	29	61	69	63	75	81	II	7	IV
144	34	48	75	63	81	94	I	9	III
145	29	62	88	63	69	63	III	6	II
146	31	67	81	56	81	75	II	6	III
147	43	77	69	13	50	13	IV	12	V
148	37	58	81	75	69	63	III	6	II
149	34	64	81	56	75	81	II	8	IV
150	30	78	63	33	44	63	III	11	V
151	39	69	63	44	75	75	II	10	V
152	41	73	69	31	50	44	IV	13	III