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Research Article

Evaluate The Relationship Between The Caregiver Burden Scale Of Care Provided To Children With Cerebral Palsy

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Introduction

Cerebral palsy (CP) is a group of neurological disorder that appears in early childhood and permanently affects body movements and muscle coordination. It is caused by abnormal development or damage to brain. The term cerebral refers to the brain, and palsy refers to loss or impairment of motor function. According to the Centre for Disease Control and Prevention (CDC), 2020, 1 to 4 in a thousand live births have cerebral palsy, making it the most common motor disability in childhood. In addition, such children can have co-morbid conditions like vision, hearing or speech problems, seizures and intellectual disability. The cause of cerebral palsy is the abnormal development of part of the brain or damage caused to the part of the brain that controls movement. Even though the cause is unknown, the common reasons are a genetic abnormality, congenital brain malformation, maternal infection, or fetal injury (at the time of birth). CP can be mild to profound according to the severity, and also, there are various kinds of CP based on the parts of the brain affected.
Caregiving situation includes the effect of the biological condition of the individual on the caregiver (in this study stroke). The patient’s functional status and caregiver’s description of care needs are part of this factor. Patient’s functional status can be a physical disability, behavioural/ mood disturbance or cognitive / communication impairment. Information on all these factors can describe the situation through which, a caregiver is going through which can affect that person’s QOL. The integration of family members is critical for a Cerebral Palsy child's transformation into a family and family-centric approach. Understanding and implementing the child in the healthcare system requires involving the parental approach to the rehabilitation program. A disabled child needs more living space. Caregivers should become more involved depending on the severity of the CP. There are numerous hurdles that aid in determining the caregiver's quality of life. A good attitude toward the caregiver's support system from family, society, and the environment appears to be a positive attitude.

LITERATURE REVIEW

Mona K Mohamed et al. (2017) developed a translated Arabic version of primary caregiver form of CPQOL questionnaire for children aged 4-12years (CP QOL-Child) and to assess its validity and reliability to be readily used in Arabic and Egyptian cultures. The original English version of CP-QOL questionnaire was translated into Arabic language using forward–backward translation method, and then a cross-sectional survey was conducted including 200 children with CP aged 4-12 years and their caregivers. Caregivers of children were interviewed to collect data about their demographic characteristics, age, and sex of their children. They were asked to fill the translated Arabic version of QOL questionnaire. Assessment of psychometric properties including test–retest reliability, internal consistency, and item internal consistency was conducted. The translated questionnaire showed excellent test–retest reliability and good internal consistency as the intra-class correlation ranges from 0.88 to 0.97 and Cronbach’s α exceeds 0.7 except for the domains of family health and emotional well-being. The majority of the items have moderate to good correlation with their domain scores. Four out of seven domains showed significant correlation with GMFCS. The translated Arabic version of CP-QOL questionnaire (Caregiver form) was valid and reliable. It could be used to assess QOL of children with CP in Arab-speaking population.

Liu Zhen Huan and Dong Shang Sheng (2018) examined the relationship between the spasticity-related pain and the quality of life about the children with CP with spasticity-related pain in China. It was a prospective, observational, one-arm multicentre study. The associations between the child and parent proxy-report QPS total scores and each domain scores of PedsQL were moderate to high. The PedsQL total scores relationship to the QPS item score was moderate. The QOL in the CP patients with SRP was worse than normal people and it was a steady long-term stage. The correlation between the spasticity-related pain and the QOL was moderate to high and negative and the result from the parent proxy-report was more evident.

Alicia K. Matthews et al. (2019) aimed to identify the determinants affecting HRQOL among mothers of children with CP. Participants in this cross-sectional study (N=180) were mothers of children with CP recruited from clinical and school-based settings in Korea. Variables examined were characteristics of child (demographic factors and disability parameter), mother (demographic factors, number of chronic conditions, Health-Promoting Behaviors (HPB), and parenting stress), and environmental factors (use of personal assistant care, leisure time and social support). Multivariate regression analysis was performed to examine the child, mother, and environmental factors associated with HRQOL. The levels of HRQOL of mothers of children with CP were very low and findings suggest modifiable factors. Decreasing parenting stress, engaging in HPB, and providing social support should be considered when developing psychosocial intervention for this population. Study results aimed at health promotion, stress reduction, and QOL improvement among parents of children with disabilities.

Martin Downes et al. (2019) conducted a study to generate a preference-based scoring algorithm for the CP six dimensions (CP-6D), a classification system developed from the CPQOL. A Discrete Choice Experiment with duration (DCEtto) was administrated to value health states described by the CP-6D classification system. These health states will be presented to members of Australian general population and parents of children with CP via an online survey. Conditional logit regression was used to produce the utility algorithm for CP-6D.

Alriksson-Schmidt et al. (2019) aimed to study HRQOL in adults with CP stratified on demographic and disability-specific factors using both experience and hypothetical-based value-sets. Cross-sectional study based on registry data from the Swedish follow-up program CPUP. The EQ-5D-3L (5 domains; self-care, usual activities, mobility, pain/discomfort, anxiety/depression) was used to measure HRQOL. Level of functioning and pain were strongly related to HRQOL, with gross motor functioning being a dominating factor. Sex and CPsubtype were not associated with HRQoL in the multivariate analysis. HRQOL was found to be high in this Swedish population of adults with CP although severe pain and reduced functioning was associated with lower HRQOL. The choice of value-set has strong influence on the HRQOL estimations, especially for lower levels of functioning.

RESEARCH METHODOLOGY

Study Design

Mixed methods- Qualitative followed by Quantitative analysis.

Sampling Technique

Purposive Sampling for Qualitative Study, Non-Probabilistic Consecutive Sampling for Quantitative Study.

Statistical analysis

The data was retrieved from Microsoft Excel analyzed with SPSS version 20. (IBM Corp, Armonk, NY, USA). Before beginning the validation process, two fundamental assumptions about item inter-correlation and sample size sufficiency were tested using Bartlett's test of sphericity and Kaiser Meyer Olkin (KMO) sampling adequacy metrics. As a result, we used principal component extraction with varimax rotation to perform exploratory factor analysis (EFA). The eigenvalues (amount of variance explained by each element) of multiple factors were kept and interpreted as factor models. Structural equation modeling was used to undertake further confirmatory factor analysis(CFA). Finally, the findings of EFA were tested, and the goodness-of-fit of the derived factor models was determined. Comparative fit indices (CFIs), the Tucker-Lewis Index (TLI), and the root mean square residual were used to measure the goodness-of-fit (SRMR). The acceptable cut-offs for these indices were CFI 0.90, SRMR 0.10, and TFI 0.90. Cronbach's alpha coefficient determines the scale's internal consistency.

DATA ANALYSIS

Quantitative Result Exploration

Table 1 Demographic characteristics of the study participants

Sl. No	Demographic Characteristics	Values
1	Age	
	Median Age of the child	8.5 (±3.8)
	The median age of the Caregivers	43.3 (±8.4)

2	Gender – Child Female Male	 46 % 54 %
3	Gender – Caregiver Female Male	 58 % 42%

Scale Development Tables

Table 2 Caregiver Burden Scale - Reliability Analysis

Item-Total Statistics			
	Scale Mean if Item Deleted	**Corrected Item-Total Correlation**	**Cronbach's Alpha if Item Deleted**
I feel completely exhausted towards the end of the day	135.463	0.225	0.831
My spouse does not provide physical support in caregiving	135.611	0.408	0.825
My family members do not provide physical support in caregiving	135.556	0.358	0.827
I am unable to take adequate rest due to caring for my child	135.509	0.314	0.828
Managing household and care of the child is a challenging job	135.426	0.185	0.832
I wish I could spend a little more time for myself	135.593	0.330	0.828
I have aches and pains in my body due to the burden of physically supporting my child	135.556	0.350	0.827
I think my physical health is decreasing day by day	135.426	0.263	0.830
Completing all demands for child care increases physical stress	135.574	0.025	0.836
I feel physical and mental stress due to caregiving	135.759	0.216	0.831
I forget about taking care of myself	135.407	-0.049	0.838
Sometimes, I cannot control me emotions	135.657	0.484	0.824
I blame myself for the condition of my child	135.944	0.454	0.823
The health condition of my child bothers me emotionally	135.593	0.414	0.826
Negative thoughts affect me	135.556	0.408	0.826
Frequently I feel low	135.444	0.318	0.828
I have a strained relationship with my spouse	135.685	0.456	0.823
Sometimes, I show my anger towards my child	135.648	0.513	0.821
I find it hard when family members differentiate between the special child and other Child/Children	135.519	0.243	0.830
Society blames the parents for having a special child	135.565	0.533	0.822
I think society needs more awareness about a special child	135.546	0.297	0.829
There is no adequate help from society for special children	135.324	0.323	0.829
I do face lots of problems while traveling along with my special child in public transport	135.361	0.546	0.821

Though there are many schemes available for children with special needs, it does not apply to all.	135.593	0.142	0.833
Still, special schools are not available everywhere	135.620	0.045	0.835
I face a financial burden because of caring for a special child	135.537	0.215	0.831
I borrow money from others to manage finances	135.713	0.239	0.831
I pawn my jewels for caring for my special child	135.648	0.455	0.823
Sometimes, it's very difficult to manage the medical expenses	135.583	0.354	0.827
I do extra work and shifts to manage the financial burden	135.648	0.382	0.826
I do not have any futuristic savings for my child.	135.593	0.439	0.825
Balancing income and expenditure are very difficult	135.472	0.240	0.830
I am in heavy financial debt because of providing care for my special child	135.704	0.577	0.819
Many parents are unaware of how to care for special children	135.602	0.225	0.831
Many parents are unaware of the disability benefits provided by the government	135.370	0.008	0.836
I do not have anyone to discuss issues related to providing care for my special child	135.426	0.247	0.831

Interpretation of Cronbach's alpha.

Cronbach's Alpha	**Internal Consistency**
α ≥ 0.9	Excellent
0.9 > α ≥ 0.8	Good
0.8 > α ≥ 0.7	Acceptable
0.7 >α ≥ 0.6	Questionable
0.6 > α ≥ 0.5	Poor

Table 2 shows that Scale means if an item is deleted, it remains the same as 135. Every question contributes almost equally to the scale (the same level of data to theset). This shows that not a single question is given more weightage. Table 2 also shows that the item to total correlation score for all questions lies below the maximum score of 0.577. This indeed shows that each question has contributedequally to the scale / or not a single question resulted in deviating the score towards one direction. This data correlation confirms that no single question strongly correlates withthe total scale. Additionally, Table 2 shows that the Cronbach's alpha when each item is removed remains stable. This indicates that no single question strongly drives the scale. And it has an excellent internal consistency. Overall, Table 2 shows that all the questions in the study scale are given equal weightage. Statistically, not a single question drives the scale alone. Cronbach's Alpha for the 36 selected items after deleting redundant questions is 0.824, which shows Good internal consistency.

CONCLUSION

The result of the study concludes that as the burden of caregivers increases, the perceived care rendering also increases. This clearly shows that they are undergoing a great responsibility to maintain the quality of care. As the child's age with cerebral palsy and the caregiver's age simultaneously increases, the physical ability to carry the child to therapy centers drastically decreases. In this case, the caregivers will look for several options like home care or self-administered care to the children depending upon their financial abilities. Or, at times, they will reduce the therapy center visit to weekly once or biweekly once, secondary to the difficulty that arises while transporting. The available special therapy schools, now focus on parent-centered care, where parents will be considered primary caregivers, and they are supposed to stay with them throughout the day. If these schools are equipped well to take care of children throughout the day, the parents/ caregivers would have an opportunity to go for some job to support themselves financially.

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