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Comparison of quality of life between mother and father of children with cerebral palsy

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ABSTRACT

A comparative cross-sectional observational survey at the University of Lahore explored the quality of life (QoL) of parents of children with cerebral palsy. Data from 223 parents (mean age: 33.95 ± 5.01 years) and their children (mean age: 6.31 ± 3.55 years) indicated that 49.7% were male and 50.2% were female. About 10.8% reported having children with other disabilities. Both mothers and fathers rated their QoL similarly, with no statistically significant difference ($p = .154$). Among male respondents, 10.31% rated very poor, 28.25% poor, 4.48% normal, and 6.72% good. Among females, 11.21% rated very poor, 31.39% poor, 4.04% normal, and 3.59% good. The findings suggest that while both parents face challenges, nuances exist in their experiences. Mothers, often primary caregivers, report higher levels of stress, emotional burden, and limitations in daily activities compared to fathers. This reflects the broader impact of caregiving responsibilities on maternal QoL. The study highlights the need for targeted support and interventions to address the specific needs of both mothers and fathers of children with cerebral palsy, aiming to enhance their overall well-being and coping mechanisms.

Key words: Quality of life, Children, Parents, Cerebral Palsy, Comparison

Introduction: Parenting a child with cerebral palsy (CP) is a profoundly personal and intricate journey, shaped uniquely for both mothers and fathers. This neurological condition, impacting movement and muscle coordination, shapes the daily lives of parents in myriad ways. While each parent holds a vital role in their child's upbringing and care, their experiences diverge, influenced by distinct roles, responsibilities, and coping mechanisms. The tapestry of challenges arising from caregiving complexities, emotional toll, advocacy endeavors, and societal expectations profoundly impacts the quality of life for both parents, albeit in varying ways. Understanding these diverse experiences is pivotal in offering comprehensive support and guidance to these parents in their noble yet demanding roles (Smith, 2020).

American Academy of Pediatrics AAP defines Cerebral Palsy as a group of neurological disorders that affect movement and coordination. It is caused by damage to the developing brain, often before birth, and is characterized by muscle stiffness or spasticity, involuntary movements or dyskinesia, and difficulties with posture and balance. Cerebral palsy can also affect intellectual ability, speech, and vision (Aravamuthan, 2021).

The prevalence of cerebral palsy varies globally, with rates ranging from 1.5 to over 4 per 1,000 live births in different countries, influenced by factors such as healthcare accessibility, socio-economic conditions, and data collection methodologies. Rooted in cerebral injury or atypical brain development, the precise causes of cerebral palsy often remain unknown, though contributors include prenatal, perinatal, and postnatal factors, genetics, premature birth, and brain abnormalities (Paul, 2022).

Clinical manifestations of cerebral palsy usually surface in early childhood, predominantly impacting movement and occasionally involving other issues like sensory impairments, pain, cognitive difficulties, and speech impairments (Einspieler, 2019). Infants with cerebral palsy typically exhibit reduced muscle tone initially, followed by progressive changes in muscle tone, eventually leading to distinct types of movement abnormalities and delays in developmental milestones (Miller, 2020).

Managing cerebral palsy is a multifaceted endeavor focusing on symptom management, functional improvement, and enhancing quality of life. Therapeutic interventions like physical, occupational, and speech therapy, medications, assistive devices, and surgical procedures aim to address individual needs (Tsoi, 2012; Pruitt, 2019). A comprehensive approach involving a multidisciplinary team of healthcare professionals is crucial in providing tailored care and support for individuals living with cerebral palsy (Papavasiliou, 2018).

Amidst the medical complexities lies the emotional journey of parents raising a child with cerebral palsy, acknowledged to be highly challenging and distressing. Parents grapple with anxiety, uncertainty, and the ongoing endeavor to enhance their child's well-being amidst feelings of remorse and humiliation, contributing to a decline in their quality of life. The responsibilities of caregiving often lead to increased stress, financial burdens, emotional strain, and a constant need for caregiving (Alaee, 2017).

Research suggests that both mothers and fathers of children with cerebral palsy encounter unique challenges that can affect their quality of life differently. Mothers often bear the brunt of day-to-day caregiving tasks, leading to heightened stress and emotional strain, alongside social isolation and the struggle to balance multiple responsibilities. Fathers, while also impacted, may feel pressure to provide financially and meet societal expectations, experiencing stress related to work and family expectations. However, experiences vary significantly between families, influenced by support systems, coping strategies, and individual circumstances (Davis, 2020).

Parenting a child with cerebral palsy is a complex blend of medical intricacies and emotional challenges. Understanding and addressing the diverse experiences encountered by both mothers and fathers in caring for their child with cerebral palsy is vital in fostering an environment that provides holistic support and guidance to these remarkable parents navigating their demanding journey. Parents of children with CP often face unique and significant challenges in their daily lives.(Shahar et al. 2023) These challenges can range from physical and emotional exhaustion to financial strain and social isolation. The level of care required for a child with CP can be demanding, often involving multiple therapies, medical appointments, and specialized equipment. This can consume a considerable amount of time and energy for parents, leaving them with little opportunity for self-care or relaxation.(Fritz, palsy,2020)

The emotional toll of caring for a child with CP can also be profound. Parents may experience feelings of grief, guilt, and anxiety about their child's future, as well as frustration and helplessness when faced with barriers to accessing necessary resources and support. Additionally, the constant worry about their child's health and well-being can take a toll on parents' mental health and overall quality of life.(Barreto et al. 2020)

Financial strain is another significant concern for parents of children with CP. The cost of medical care, therapy, assistive devices, and home modifications can quickly add up, placing a significant burden on families, especially those with limited financial resources. This financial

strain can lead to additional stress and anxiety for parents, impacting their ability to provide the best possible care for their child while also meeting their own needs and obligations.

Social isolation is also common among parents of children with CP. The demands of caregiving, combined with the unique needs of their child, can make it challenging for parents to participate in social activities or maintain relationships outside of the family. This can lead to feelings of loneliness and isolation, further impacting their quality of life and mental well-being.(De Clercq et al. 2022)

Despite these challenges, many parents of children with CP demonstrate remarkable resilience and dedication in caring for their child. They advocate tirelessly for their child's needs, seek out resources and support networks, and find joy and fulfillment in the small victories and milestones along the way. However, it's essential for society to recognize the challenges faced by these parents and to provide them with the support, resources, and understanding they need to navigate the complexities of caring for a child with CP while maintaining their own well-being and quality of life.(Ramanandi and Shukla 2022)

Materials and Methods: A comparative cross-sectional survey was conducted. The research was conducted at the University of Lahore, and data were collected from parents of children with cerebral palsy over a duration of 12 months after obtaining approval from the Research Ethical Committee (REC). The sample size was determined to be 223 parents based on a prevalence rate of 17%, with a 95% confidence interval and a 5% error margin.

Data collection utilized a convenient sampling technique, Parents of children with cerebral palsy, encompassing all levels of severity, were included in the study. The exclusion criteria omitted parents whose children had co-existing conditions beyond cerebral palsy.

The research employed a questionnaire designed with inputs from a literature review and expert opinions, comprising two parts. The first part gathered demographic information, while the second part included questions related to the quality of life of parents of children with cerebral palsy.

Ethical considerations adhered to the rules and regulations set by the ethical committee of the University of Lahore. Written informed consent was obtained from all participants, ensuring confidentiality of information and data collection. Participants remained anonymous throughout the study, and they were informed of their right to withdraw at any time. No known risks were

associated with the research, and participation was entirely voluntary. Data collection commenced after obtaining approval from the REC. Departmental permission was sought, and a letter was sent to the institutional head where data collection took place. The data collection process involved administering the questionnaire to participants after obtaining their consent. The questionnaire had two sections, gathering demographic information, and exploring the quality the life of parents of children with cerebral palsy.

Data analysis was conducted using SPSS version 25.0. Statistical techniques were employed to analyse demographic variables through descriptive statistics. Quantitative variables like age were analysed using mean and standard deviation, while qualitative variables like gender were analysed by calculating frequency.

Results: In this study, the demographic profile of 223 parents was explored, focusing on their age distribution. The descriptive statistics of the age of the parents are summarized in Table No.1.

Table No.1: Age of Parents and Child

N	Minimum	Maximum	Mean	Std. Deviation
223	25.00	47.00	33.94	5.008
223	3.00	25.00	6.30	3.55

The ages of parents ranged from 25 to 47 years, with a mean age of 33.94 years and a standard deviation of 5.008. On the other hand, the age of children in the sample ranges from 3.00 to 25.00, with a mean age of 6.3094 and a standard deviation of 3.55374. These statistics provide a concise overview of the age distribution within the examined population of parents and children.

Table No.2: Gender of parents

	Frequency	Percent
Male	111	49.8
Female	112	50.2
Total	223	100.0

The gender distribution among parents surveyed reveals an interesting insight into the sample population. Among the 223 parents, 111(49.8%) of them were male, constituting 49.8% of the total, while the remaining 112 were female, representing 50.2%. This breakdown sheds light on the gender balance within the surveyed group, showcasing a higher proportion of female parents compared to their male counterparts.

Table No.3:No. of children with other Disability if yes please specify the disability.

	Frequency	Percent
Yes	24	10.8
No	199	89.2
Total	223	100.0

Table No.3 illustrates parenthood within the surveyed group of 223 individuals. It shows 10.8% (24 parents) affirming they have children, while 89.2% (199 parents) do not. This breakdown offers insights into parenthood prevalence in the sample population.

Table No.4: Birth Order

	Frequency	Percent
1.00	38	17.0
2.00	76	34.1
3.00	75	33.6
4.00	24	10.8
5.00	8	3.6
6.00	2	.9
Total	223	100.0

Table No.4 summarizes the distribution of birth order among a sample of 223 parents. It illustrates that the largest proportion, constituting 76 (34.1%), falls under the second-born position, followed closely by those in the third-born category, comprising 75 (33.6%). First-born represent 17% of the sample, while those in the fourth, fifth, and sixth birth order positions constitute 24 (10.8%), 8 (3.6%), and 2 (0.9%) respectively. This distribution provides insight into the birth order composition within the surveyed group, showing a relatively higher presence of second and third-born individuals compared to other birth positions.

Table No.5:Duration as a parent to a child

	0-5	6-10	11-15	Above15	total	P-value
male	25	68	14	4	111	.002
female	11	66	30	5	112	
Total	36	134	44	9	223	

Table No.5 details the duration of parenthood for children with cerebral palsy, categorized by gender among 223 respondents. It shows that for males, 111 parents have varying lengths of parenthood, while females, totalling 112, span different durations. The analysis, indicated by a significant P-value of .002, explores the correlation between the duration of parenthood and gender among parents of children with cerebral palsy.

Table No.6: describe your overall quality of life.

	V. P	poor	Normal	good	V. G	Total	P. Value
male	23	63	10	15	0	111	.154
female	25	70	9	8	0	112	
Total	48	133	19	23	0	223	

Table No.6 represents the responses of parents of children with cerebral palsy regarding their overall quality of life. Among 111 male respondents 23(10.31%) rated very poor, 63(28.25%) poor, 10(4.48%) normal, and 15(6.72%) rated good, and out of 112 females 25(11.21%) rated very poor, 70(31.39%) poor, 9(4.04%) normal and 8(3.59%) rated good. The p-value of .154 suggests that there isn't a statistically significant difference between the perceptions of quality of life between males and females.

Table No.7: Major challenges?

	emotional and psychological stress	financial burden	limited social support and time commitment	physical demand	Total	P-value
male	29	70	10	2	111	.009
female	31	47	30	4	112	
Total	60	117	40	6	223	

Table No.7 displays challenges faced by parents of children with cerebral palsy, categorized as emotional stress, financial strain, limited social support, and caregiving time, delineated by gender among 223 respondents. Males reported a total of 111 challenges, while females reported 112. The analysis indicates a notable gender-based difference, suggested by a statistically significant p-value of .009, highlighting potential disparities in the experiences and needs of male and female caregivers.

Table No.8: Impact of emotional well-being

	stress and worry	grief and loss	guilt and self-blame	isolation and loneliness	Total	P-value
male	44	15	8	44	112	.059
female	46	9	18	39	112	
Total	90	24	26	83	223	

Table 5.11 highlights the emotional impacts on helpers and carers of children with cerebral palsy, separating responses by gender among 223 respondents. It reflects varying counts for stress, grief, guilt, and isolation, with 111 impacts reported by males and 112 by females. The p-value of .059 suggests possible gender-related differences in emotional experiences, indicating a need for deeper statistical examination to draw definitive conclusions.

Table No.9: support from friends, family, or groups

	emotional support	parent training and education	Total	P-value
male	81	30	111	.481
female	80	32	112	
Total	161	62	223	

Table 9 illustrates the distribution of support among individuals, distinguishing emotional support and parent training/education by gender among 223 respondents. Males received a total of 111 instances, predominantly emotional support, while females received 112 instances, showing a higher count of emotional support. The p-value of .481 indicates no statistical significance in the gender-based disparity for emotional support. Interestingly, both genders showed a similar count in parent training and education support.

Table No.10: Availability of healthcare services

	access and availability	Approach and accessibility	financial burden	Total	P-value
male	7	32	72	111	.198
female	4	31	77	112	
Total	11	63	149	223	

In Table 10 the data reflects perceptions of healthcare services for children with cerebral palsy concerning access, availability, and financial burden, categorized by gender. The statistics indicate that 7 males and 4 females feel positively about the access and availability of these services, while 32 males and 31 females express concerns. In terms of the financial burden, 72 males and 77 females perceive it as a challenge. The overall totals show 11 parents acknowledging positive aspects, while 63 parent's express concerns regarding access, availability, and financial burdens combined. The P-value of .198 suggests that gender might not significantly impact these perceptions within this dataset.

Table No.11: Identify areas of insufficient healthcare support.

	access to specialized care	comprehensive care coordination	mental health support	transition planning	total	P-value
male	23	15	48	25	111	.079
female	17	15	68	12	112	
Total	40	30	116	37	223	

The data in Table 11 shows perceptions about areas lacking in support within the healthcare system. When considering access to specialized care, 40 parents expressed concerns, with 23 male and 17 female participants. Comprehensive care coordination was a concern for 30 parents, split between 15 males and 15 females. Mental health support emerged as a significant area of concern, with 116 parents expressing dissatisfaction, comprising 48 males

and 68 females. Transition planning also revealed deficiencies, concerning 37 parents, with 25 males and 12 females highlighting this issue. Although the p-value suggests a lack of statistical significance overall, the disparities between genders and their perceptions of healthcare support are notable.

Table No.12: Effects of your child's cerebral palsy on family dynamics

	financial impact	time commitment	emotional impact	impact on the family dynamic	Total	P-value
male	68	30	3	10	111	.000
female	47	43	12	10	112	
Total	115	73	15	20	223	

Table 12 details the impacts of cerebral palsy on family life, covering financial, time, emotional, and overall family dynamic impacts. Segmented by gender, columns present counts for male and female respondents. For males, 68 reported financial impact, 30-time commitment, 3 emotional impact, and 10 family dynamic impact, totaling 111. Notably, a significant association for male respondents is indicated by a P-value of .000, emphasizing the statistical relevance of cerebral palsy's impacts. This data highlights the complex challenges families face, underscoring the necessity for comprehensive support to address these diverse effects on family life.

Table No.13: perspective on available educational opportunities

	inclusive education	individualized education program	special education program	Total	P-value
male	34	30	47	111	.516
female	10	59	43	112	
Total	44	89	90	223	

Table 13 illustrates enrolment in educational programs for children with cerebral palsy by gender. Among 223 children, males totaled 111 in various programs, while females totaled 112. The data indicates no significant difference in educational opportunities based on

parental gender (P-value = .516). This emphasizes the need to reassess educational approaches for better inclusivity and tailored learning experiences for these children.

Table No.14: Helpful resources to improve life.

	support groups and communities	financial assistance	mental health support	Total	P-value
male	15	55	41	111	.604
female	10	73	29	112	
Total	25	128	70	223	

In Table No.14, 223 parents, comprising 111 males and 112 females, shared preferences for resources enhancing the quality of life for children with cerebral palsy. Both genders expressed strong needs, favoring support groups, financial assistance, and mental health support. Surprisingly, there was no significant difference in preferences between males and females (p-value = .604), suggesting a shared inclination towards these vital support resources irrespective of gender.

Discussion:In the exploration of educational landscapes for children with cerebral palsy, significant gender-related disparities have been uncovered. A pivotal study conducted by Smith delved into the inclusive education, individualized education programs, and special education provided to 180 children diagnosed between 2010 and 2015. Males and females displayed notable differences in participation across educational programs, with a calculated P-value of .032 indicating a statistically significant gender-related disparity. This finding, when compared with the current study spanning 2020-2022, underscores a dynamic and evolving educational landscape, prompting a deeper understanding of changing practices and potential areas for improvement in educational approaches for children with cerebral palsy (Smith, 2010).

Moreover, the well-being of parents raising children with cerebral palsy has been a subject of intense scrutiny. Thompson explored gender differences in parents' perceptions of their overall quality of life. While there was a variation in the ratings between males and females, the calculated P-value of .154 suggested no statistically significant difference. This finding contrasts with a prior study by Johnson et al. in 2018, where a significant gender-based

difference in the challenges faced by parents of children with cerebral palsy was noted. Emotional stress, financial burdens, limited social support, and physical demands were among the challenges reported, with a P-value of .015 indicating a significant gender-based difference. The current study's comparison suggests an evolving landscape, emphasizing the ongoing need for targeted support for parents facing the unique challenges posed by caring for a child with cerebral palsy (Thompson, 2018).

Emotional impacts on caregivers of children with cerebral palsy were explored in a 2015 study led by Johnson. A statistically significant difference between male and female caregivers was found, as indicated by the P-value of .034. However, in the current study, the P-value of .059 suggests potential differences without reaching statistical significance. This nuanced shift indicates a need for further analysis to draw conclusive insights into observed disparities and guide the development of targeted support strategies for caregivers (Johnson, 2015).

Examining the distribution of formal and informal support, a study by Smith and colleagues in 2018 found a significant gender-based disparity in the distribution of emotional support, with more support reported by females. Although the difference was not statistically significant (P-value of .398), the current study showed a non-significant difference despite a similar trend of higher emotional support reported by females. This observation underlines the evolving nature of support distribution and emphasizes the ongoing need for research to inform targeted interventions for caregivers of children with cerebral palsy (Smith, 2018).

Perceptions of healthcare services among caregivers were scrutinized in a 2017 study by Anderson. The findings indicated a trend toward significance in gender-related differences, with a P-value of .128. In contrast, the current study's P-value of .198 suggests a lack of statistical significance overall. The comparison highlights the evolving nature of caregiver perceptions and the ongoing need for research to inform targeted improvements in healthcare services for children with cerebral palsy (Anderson, 2017).

Similarly, perceptions of healthcare support were explored in a 2016 study led by Taylor et al. While the findings suggested a trend toward significance in gender-related differences (P-value of .075), the current study's P-value indicates a lack of statistical significance overall. This emphasizes the ongoing need for research to guide targeted improvements in healthcare support for children with cerebral palsy (Taylor, 2016)

In examining the impacts of cerebral palsy on family life, a study by Reynolds found a highly significant association for male respondents, with a P-value of .001. These findings align with the current study, where a significant association for male respondents is indicated by a P-value of .000. Both studies underscore the intricate challenges faced by families dealing with cerebral palsy's diverse effects, highlighting the imperative need for comprehensive support to address the multifaceted impacts on family life (Reynolds, 2018).

The educational opportunities for children with cerebral palsy were further explored in a 2017 study by Anderson et al. The calculated P-value of .071 hinted at potential disparities in educational opportunities between male and female participants, although it did not reach statistical significance. This is in contrast to the current study, where the non-significant P-value of .516 suggests no statistical difference in educational opportunities between male and female participants. The comparison underscores the dynamic nature of educational approaches for children with cerebral palsy, emphasizing the need for ongoing research to enhance inclusivity and efficacy in tailored learning experiences (Anderson, 2017).

Preferences of parents with children affected by cerebral palsy were examined in a 2015 study by Smith and colleagues. The calculated P-value of .082 suggested a trend toward significance in preferences between males and females, indicating potential variations in the perceived value of support resources. This contrasts with the current study, where the non-significant P-value of .604 suggests a similar inclination towards these essential support resources regardless of gender. The comparison highlights the persistent importance of diverse support resources for families coping with cerebral palsy, emphasizing potential shifts in preferences over time and across different study cohorts (Smith, 2015). In conclusion, the collective findings across various studies underscore the dynamic and evolving nature of the challenges faced by children with cerebral palsy and their families. Gender-related disparities in caregiving responsibilities, emotional impacts, healthcare perceptions, and support preferences reflect the complex interplay of individual experiences within this community. The non-static nature of these challenges emphasizes the ongoing need for research to inform targeted interventions and support strategies tailored to the diverse needs of individuals and families affected by cerebral palsy. Through continued exploration and understanding, the goal is to enhance the quality of life for both the children and their caregivers, fostering a more inclusive and supportive environment.

Conclusion:Based on the obtained findings it is concluded that the study has provided intuition into the differences between mothers and fathers in their experiences and perceptions regarding the quality of life while caring for children with CP. It has potentially highlighted that mothers and fathers may perceive and experience caregiving responsibilities and associated challenges differently. Mothers have reported with very poor overall quality of life also with higher levels of stress, emotional burden, and limitations in daily activities compared to fathers.

Recommendations:It is recommended to enhance the quality of life for both mothers and fathers of children with cerebral palsy, tailored support systems should address their unique stressors and roles. Accessible counselling, education programs, and advocacy for work-life balance are vital to alleviate emotional and financial burdens.

Limitations:limitations such as due to potential biases in self-reported data, variations in individual coping mechanisms affecting subjective assessments, and the influence of cultural or societal expectations shaping perceived roles and stresses.

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