ORIGINAL ARTICLE

Quality of life of mothers having children with Down syndrome

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ABSTRACT

Background: A mother's Quality of life (QoL) is essential not only for her own well-being but also for providing better care to her child.

Objective: To assess the QoL of mothers having children with Down syndrome.

Methods: A cross-sectional analytical study was conducted in ten special needs schools catering to intellectual disabilities from September 2023 to March 2024 after Institutional ethical approval (IRB Ref letter # M-22/82/-CM). The study population was mothers of children with Down syndrome. A sample size of 37 was calculated on the WHO sample size calculator, doubled to 74, and the questionnaire was administered to 100 mothers. We included mothers of children diagnosed with DS, willing biological mothers who have one child with Down syndrome, and all other normal children. Whereas, single mothers, mothers having a child with Down syndrome who also suffered from another dual diagnosis, and mothers having another chronically sick or disabled child were excluded. A convenient sampling technique was applied. Data was collected using a standardized, validated WHOQOL-BREF instrument.

Results: The total QoL mean score for mothers was 84.45±14.33. Higher maternal education ($p=0.007$) and having a child older than 10 years ($p<0.001$) were significantly associated with increased mean QoL scores. Gender of the child and household income showed no statistically significant ($p>0.05$) associations.

Conclusion: Mothers with a higher education level, a child with Down syndrome of >10 years, and a better family socio-economic status had a higher quality of Life.

Key Words: Down syndrome; quality of life; mothers

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INTRODUCTION

Worldwide, the incidence of Down syndrome (DS) is 1 in every 1000 live births; thus, it turns out to be the most common genetic cause of intellectual disability among children.[1] However, data regarding its prevalence in developing middle and lower-income countries is very scant. In Pakistan, the total estimated Prevalence of intellectual disabilities is 17%; out of which 8% is contributed by mental retardation; and DS is among one of the commonest disabilities in this primary group.[2]

Another study from Lahore, Pakistan, states that 1 in every 300 babies in Pakistan is diagnosed with DS.[3] In India, the overall incidence of DS is 1-1.4/1000 live births, which is higher compared to various other countries that are providing prenatal diagnosis of DS.[4]

DS, a genetic chromosomal disorder, is the most commonly occurring developmental disorder, and raising a child with DS is challenging for the family in various ways.[5] Past studies have revealed that such families do experience emotional exhaustion, stress, and depression.[6] Parents are stressed and anxious about their child's future, social neglect of the child, and their work-life balance, all influencing the Quality of Life (QoL) of parents in one way or another.[7] Most of the studies conducted on the families of children with DS are done in the developed world, and few in developing countries.[8] In one study on QoL of mothers with DS children, conducted in Malaysia, it was reported that mothers' background characteristics, like rural or urban, household income, marital status, and maternal age, were significantly correlated with their QoL, with the lowest domain score for environmental support.[9] Previous research has provided growing evidence that across cultures, various social determinants of health, like the education level of the parent or caretaker, family income, psychosocial support resources and services, and societal and family attitudes towards the DS child, all have a significant impact on the families with DS children.[10] A recent study conducted in Lahore, Pakistan, assessed the anxiety and depression levels among parents of children with intellectual disabilities and found that 75% of the parents had significant levels of stress and depression.[11] Another previous study conducted in India explored the QoL of parents and found that most mothers reported low QoL with a mean of 52.82±15.38 in the overall score of the WHOQOL-BREF questionnaire.[12]

Past global studies have revealed that parents who were raising children with intellectual disabilities experience far more stress as compared to parents raising typical children; disability of the child may burden the family, more specifically the mother who is the primary caregiver for such a child.[13] The QoL of parents raising intellectually delayed children as DS, face significant challenges at all times in the life of the child; in terms of caring needs, social support services, additional responsibility, environmental factors, family dynamics, etc.[14]

In local setup exploration in this area, to study the self-reported QoL of parents raising children with DS is scant. Hence, this study explored and assessed the mean QoL of mothers raising children with DS and the association between the QoL of mothers and sociodemographic factors.

Operational definitions used in this study are:

(1) QoL was assessed in terms of mean QoL score, measured through self-reporting, by the mothers through a validated quantitative instrument, WHOQOL-BREF, developed by the World Health Organization. It has proven to be reliable in measuring QoL in populations across cultures.

(2) Down syndrome: Children are easily identified by their characteristic visible features and confirmed by chromosomal analysis.

METHODS

It was an analytical cross-sectional study conducted in special needs training centers and schools in the public sector of Lahore that cater to intellectual disabilities (Down syndrome, Cerebral Palsy, Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder). The special education centers in Aziz Bhatti town, Ravi town, Wahga town, Shalimar town, Nishtar town, Raiwind, Thokar Niaz Baig, Shadab Training Institute of Special Education, National Special Education Center, Johar town, and Vocational Training Center for disabled persons, Johar town. The study was conducted from September 2023 to March 2024 after taking approval from the Institutional Review Board (IRB).

The study population included mothers of children with DS from the centers mentioned above. The sample size was calculated using the WHO sample size calculator: a margin of error of 5%, a confidence interval of 95%, a mean QoL score of 52.82, and taking an expected SD of 15.38.[12] The estimated sample size was 37 mothers who were raising a child with DS. To increase the validity of the study, the sample size was doubled to 74, and, catering to a non-response rate of 20%, the questionnaire was administered to a sample of 100 mothers. We included mothers of children diagnosed with DS, willing biological mothers who have one child with DS, and all other normal children. Whereas, single mothers, mothers having a child with DS who also suffered from another dual diagnosis, and mothers having another chronically sick or disabled child were excluded. A non-probability, convenient sampling technique was applied to recruit the mothers for this study, considering their availability during the interview.

A special session for data collection was requested by a researcher and duly facilitated by management. The researcher was present in the session herself to explain the study to the mothers and get the questionnaire filled in physically. Informed written consent was taken from the mothers, and all due ethical considerations were duly observed to secure the data.

WHOQOL-BREF, developed by the World Health Organization, was employed to collect data on the QoL of mothers.[15] The instrument also had a section to collect data on the socio-demographic variables of mothers (age, level of education, working housewife, financial status if working, living in rented/ owned home, suffering from any long-term illness), and family (total number of children, father's age, father's level of education, father's job status, father's financial status, family type, any other offspring with a chronic illness, a second child with any other disability).

WHOQOL-BREF, developed by the World Health Organization, is a validated and standardized instrument with proven reliability to measure QOL in populations across cultures. It has got 02 general questions at the start that ask about the individual's overall perception of QOL and their health. Then there are a total of 26 items divided into 04 domains of the questionnaire that enquire about different aspects in each domain: domain 1- physical health; domain 2- psychological health; domain 3- social relationships; and domain 4- environment. Scores in these four domains mean an individual's perception of QOL in each particular domain. Three items (Q 3, 4, & 26) are negatively phrased and are coded in reverse for scoring purposes. According to the guidelines, the domain and total scores are scaled positively, i.e., higher mean scores denote higher QOL and vice versa. The score of the items in each domain is used to calculate the overall total score of QOL.

Ethical Approval

The study was conducted from September 2023 to March 2024. Data collection started after ethical approval from the IRB of the Akhtar Saeed Medical and Dental College, Lahore, Pakistan (IRB Ref letter # M-22/ 82/- CM; Dated: 31.5.22) and College of Physicians and surgeons Pakistan (CPSP) Lahore Regional Office (Ref letter # CPSP / REU / COM-2022-085-379; Dated: August 29, 2023). Approval was also taken from the Punjab Special Education Department to get access to the relevant special education school/training centers for data collection from the mothers (Ref letter # DGSE-AD (PSY)/ MISC/ 2021/ 7838) dated 13.5.22.

Furthermore, the school's administration was involved in accessing the mothers for data collection.

Statistical Analysis

Data was entered and analyzed using SPSS 23. Descriptive statistics are calculated, and Quantitative data, i.e., age and QoL score, are presented as mean ± SD. Qualitative variables (gender of the child and the first two overall questions) are presented as frequencies and percentages. Stratification is done to adjust the effect of the conventional effect modifiers (age of the DS child, gender of the DS child, age of the mother, socioeconomic status) as well as the effect of some other factors that can affect the association with QoL in mothers as predictors (number of siblings, education of mother and father, working status of mother and father). A post-stratification t-test is applied to determine the effect of effect modifiers on the QoL of mothers.

RESULTS

Among the study participants, 43 mothers were under ≤ 35 years of age and 57 were over ≥ 35 years of age. Nineteen mothers had ≤ 2 children, and eighty-one had > 2 children; 27 mothers had a nuclear family type, and 73 mothers had an extended family type. The sociodemographic profile of the parents and children with DS is presented in Table 1.

Table 1: Socio-demographic profile of parents and children with Down syndrome

Variable	n (%)
Mothers' education	
Intermediate and below	62 (62.0)
Above intermediate	38 (38.0)
Working status of mothers	
Professional	27 (27.0)
House wife	73 (73.0)
Fathers' education	
Inter and below	76 (76.0)
Above inter	24 (24.0)
Household income (PKR)	
≤100,000	52 (52.0)
>100,000	48 (48.0)
Profile of children	
Age	
≤10 yrs	26 (26.0)
>10 yrs	74 (74.0)
Gender	
Male	38 (38.0)
Female	62 (62.0)

The age range of mothers was 19-61 years, with a mean age of 37.9±7.10. The minimum age for DS children was 3 years, the maximum was 35 years, and the mean was 13.17±4.94.

In the study sample, none of the mothers had a QoL total score below 50; the majority (87%) had a QoL raw score in the range of 51-100; and only 13% had a QoL total score >100.

Approximately 25.3% of the variability in the outcome variable (QoL) is explained by the independent variables included in the model. Our study found that the Mean QoL score increased by 9.08 units among mothers with an education level above intermediate (p=0.007).

Table 2: Perception of mothers regarding their Quality of Life and health

Category	n (%)
How would you rate your Quality of life?	
Poor	02 (2)
Neither poor nor good	75 (75)
Good	20 (20)
Very good	03 (3)
How satisfied are you with your health?	
Dissatisfied	09 (9)
Neither dissatisfied nor satisfied	32 (32)
Satisfied	55 (55)
Very satisfied	04 (4)

Table 3: Mean quality of Life (QoL) score of mothers

Variable	n	Minimum	Maximum	mean±SD
QoL	100	54.0	139.0	84.45±14.33

Table 4: Comparison of mean Quality of Life scores across sociodemographic subgroups

Variables	mean ± SD	p value
Age of the DS child		
≤10 yr	75.88 ±7.370	0.000*
>10 yr	87.45 ±14.98	
Gender of the child		
Male	82.09 ±13.67	0.035*
Female	88.28 ±14.73	
Number of children		
≤2	82.36 ±9.95	0.485
>2	84.93 ±15.18	
Mothers' age		
≤35 yr	82.95 ±14.05	0.367
>35 yr	85.57 ±14.56	
Mothers' education level		
≤intermediate	81.22 ±13.18	0.004*
>intermediate	89.71 ±14.74	
Fathers' education level		
≤intermediate	82.35 ±13.83	0.014*
>intermediate	90.81 ±14.70	
Fathers' socio-economic status		
≤100,000	80.95 ±13.24	0.028*
>100,000	87.43 ±15.15	

*DS=Down syndrome; t-test was applied. *p <0.05 is statistically significant.*

The mean QoL score increased by 11.49 units among mothers who had a DS child above the age of 10 years (p=0.000). The mean QoL score increased by 0.63 among mothers with a socioeconomic status of >100,000/ month, though with an insignificant p-value. The mean QoL score decreased by 4.91 units among mothers with a male child with DS, with an insignificant p-value.

DISCUSSION

This study assessed the QoL among mothers of children with DS. It revealed that the QoL was significantly influenced by factors such as the child's age and gender, the education levels of both parents, and the father's socioeconomic status. Among these, the mother's education and the child's age strongly correlate with maternal well-being. These results highlight the importance of both child-related and parental factors in shaping the QoL for mothers caring for children with DS.

The birth of a child with a developmental disorder is a huge challenge to the parents and immediate family, and raising such a child to their optimum level of capacity is an even bigger challenge. Previous literature has shown that this whole journey of mother and child affects the QoL of parents, specifically the mother.[16] Mothers in our local culture are the primary caregivers of a child, and in cases where she has to raise a child with DS and her other typical children, it becomes an arduous task for her. This responsibility becomes heavier on her shoulders and mind when she faces numerous challenges related to the rehabilitation process of her differently abled child; inside and outside the home. Though many of these challenges are directly linked to the child's development and QoL, they indirectly burden the mother and grossly affect her.[17] However, little focus and attention have been placed upon the health and QoL of mothers/caregivers of children with developmental disabilities.[18]

The baseline socio-demographic characteristics of mothers and children with DS in this study are similar to those of another prospective study conducted in Saudi Arabia, which explored the QoL of 261 caregivers having children with DS.[19]

The overall self-reported perception of mothers in the present study, regarding their QoL, is supported by the study conducted in Saudi Arabia, which stated: participating caregivers reported having 'good-satisfactory' levels of the QoL when asked about their overall perception of QoL.[19] Present findings are also consistent with another study that stated 84% of the respondent mothers had good QoL, and 55% were satisfied with their mental health.[20]

The current study found an overall mean QoL score of 84.45±14.33; none of the mothers had a total score below 50. A majority (87%) had a QoL score in the range of 51-100, and only 13% had a raw total score of >100. This finding of our study is supported by another study conducted in India, which found an overall QoL score mean of 52.82±15.38, on WHO-QOL BREF.[8] This finding is consistent with another previous study that found a higher QoL total score for the participating mothers.[19] A probable reason for this higher score in the present study could be the influence of the respondents' religious beliefs, to some extent. However, the one concrete factor of comprehensive and affordable rehabilitative social support that indirectly contributes to the enhancement of QoL for these mothers is minimal in our local setup. Hence, the researcher could identify religious beliefs as the probable reason for these high QoL scores, as each respondent voiced these many times during their interview. Assessing the relation of religious beliefs with QoL was not in the scope of this study.

This study used post-stratification analysis to examine the effect modifiers' effect on mothers' QoL scores. Approximately 25.3% of the total study population shows variability in the QoL scores about the input factors used in this study.

A significant relation of QoL of mothers was found with >10 years’ age of DS child; female gender of the child; high level of mother’s education; high level of father’s education; and father’s high socio-economic status. These findings are similar to the findings of another study that found the higher educational levels of mothers are associated with better QoL.[21] In another study conducted in Brazil, positive and significant correlations were found between better QoL and higher educational and high socio-economic levels.[20] However, the result in the present study shows that the mother’s age does not have a significant relation with a higher QoL score, which is opposite to the results of the previous study by other researchers. Previous studies indicate that a mother’s age can significantly impact their QoL, improving the association between mothers and their children, and the mature and older age of mothers is related to QoL enhancement.[22] These findings of the present study are also consistent with another previous study stating that the parents' education level, number of children, average monthly income, and socioeconomic status had a significant association with the QoL of the caregivers.[23]

CONCLUSION

Mothers who had a higher education level, a child with Down syndrome of >10 years, and a better socio-economic status of the family had a higher quality of Life.

Strengths of the study

This is one of the very few studies that have studied the quality of life in mothers having children with Down syndrome, in our local setup and all mothers (in the sample frame from all special needs centers/ schools in Lahore) who have a child with Down syndrome were included in the sample.

Limitations of study and future recommendations

It was a cross-sectional study, along with the time constraint and getting access to the mothers. The WHOQOL-BREF is a generic scale for assessment of quality of life and not specific to the caregivers (mothers). Emotional strain and caregiver burden cannot be measured by this scale. It may lack sensitivity to measure some unique psychosocial stressors that most mothers face, like stigma, educational, career, and health issues about their children. The general belief (faith) system in the local society (regarding the aspect being studied) had a major influence on the participants’ responses.

The quality of life of mothers having a child with Down syndrome needs to be studied with a tool that specifically measures the outcome among such mothers and caregivers. A tool that encompasses all other aspects of their life, like emotional strain, caregiver burden, stigma, and issues of rehabilitation for their child. There is a need for the development of one such specific tool in our local context.

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AUTHOR’S CONTRIBUTIONS:

- **SS:** Conception of study, study design, data acquisition & analysis, manuscript drafting
- **IM**: Conception of study, interpretation of data, manuscript drafting, critical review

All authors approved the final version to be published and agreed to be accountable for all aspects of the work, ensuring that any questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved

CONFLICT OF INTEREST:

None

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