QUALITY OF LIFE OF MOTHERS OF CHILDREN WITH DOWN SYNDROME

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ABSTRACT

BACKGROUND

Down syndrome is one of the common chromosomal abnormalities in humans. It occurs in about one per 700 - 800 babies born each year. The quality of life of the family may be related to the medical problems in the child, parental awareness and attitude to this differently abled child and other parental factors as their personality, anxiety, depression and stress. Hence, this study was undertaken to assess the quality of life of mothers of children with Down syndrome with respect to differences in selected child related and parent related socioeconomic variables.

MATERIALS AND METHODS

31 children with Down syndrome who presented to the outpatient department and Down Syndrome Clinic at the Institute of Child Health, Kottayam from August to December 2016 were enrolled after getting informed consent and IRB approval. Social and demographic data of children and mothers in the study group by purposive sampling were entered into a proforma and detailed medical examination was conducted and recorded in the Paediatric medical examination sheet by the investigator after obtaining informed consent. The mothers were administered with WHO-QOL BREF Questionnaire (Malayalam) to assess the QOL after proper explanation. Data were analysed with statistical tests as mean and standard deviation for descriptive data and Mann-Whitney U test and Kruskal-Wallis test for nonparametric data.

RESULTS

Medium Quality of Life was reported by most of the mothers with mean of 52.82 ± 15.38 overall score WHO QOL BREF questionnaire. Higher mean score was observed in the social relationship domain. QOL scores were better in rural joint families and upper middle class families. This may be due to the better social and psychological support in the family. When the educational status of the spouse is higher, mothers reported a low QoL score, though no such difference was seen with the educational status or occupation of mothers. The maternal QoL scores did not show significant differences with reference to child related variables as age, sex, birth weight, gestational age or medical illness in the child.

CONCLUSION

Medium Quality of Life was reported by most of the mothers of children with Down Syndrome. Better QoL was observed in rural joint families and upper middle class families; not affected by child related variables.

KEYWORDS

Down Syndrome, Quality of Life, Caregiver Burden, Parenting Stress.

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BACKGROUND

Down Syndrome (DS) is the commonest genetic disorder in children with an incidence of 1 in 700 - 800 live births. The child with DS poses a significant challenge to the family and rearing these children to the optimum level is still more challenging. The birth of a DS child often contributes much stress and anxiety to the parents. When compared to normal children, these babies require frequent medical attention and supportive care. Proper medical care and parental education can improve their quality of life and life skills.¹

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Quality of Life (QoL) as a concept has been increasingly accepted as an important outcome measure in patients and caregivers of chronic illnesses.² QoL includes the conditions of life resulting from the combination of the effect of complete range of the factors such as those determining health, happiness and a satisfying occupation, education, social and intellectual attainments, freedom of actions and freedom of expression. The concept is further understood as an individual's perception of their position in life in context of the culture and value systems in relation to their goals, expectations, standards and concerns. The presence of a child with developmental disability in the family calls for a lot of adjustment on the parents and other family members. Although, the unmet needs of parents of children with disabilities are universally linked to stress, there could be some cultural differences in the way this stress impacts parents and their quality of life.

Hence, this study was conducted to assess the quality of life of mothers of children with DS. Quality of life of the family

depends on the wellbeing of a child, which in turn depends on the functional ability of the child, socioeconomic factors and support systems. Maternal psychological factors like anxiety and depression may be affecting the child care and resilience on the part of the mother is essential for the stable background of the family.³ As the mother is the primary caregiver and support for the child, her physical and mental stability will certainly affect the quality of life of the disabled child. Among parents, mothers perceive more stress and burden in caring for their disabled children than fathers.⁴

Objectives

To assess the quality of life of mothers of children with Down syndrome with respect to differences in selected child and parent related variables.

MATERIALS AND METHODS

31 children with Down syndrome who presented to the outpatient department and Down Syndrome Clinic at the Institute of Child Health, Kottayam from August to December 2016 were enrolled after getting informed consent and IRB approval. Social and demographic data of children and mothers in the study group by purposive sampling were entered into a proforma and detailed medical examination was conducted and recorded in the Paediatric medical examination sheet by the investigator after obtaining informed consent. Detailed interview was conducted for mothers and data recorded. The mothers were administered with WHO-QOL BREF Questionnaire (Malayalam) to assess the QoL after proper explanation. Data were analysed with statistical tests as mean and standard deviation for descriptive data and Mann-Whitney U test and Kruskal-Wallis test for non-parametric data.

RESULTS

Out of the 31 children with DS, 16 were males and 15 were females. 11 (35.6%) were less than 1 year, 15 (48.3%) children 1 - 5 years and 5 (16.1%) children 5 - 12 years of age. Mean age of the study group was 1.48 ± 0.51 years; 9 (29%) were from nuclear family and 22 (71%) from joint family. Contrary to the belief that children with DS are born to elderly mothers, 12 (38.7%) were below 30 years of age at the time of conception of their DS baby. Mean age at conception was 30.6 ± 5.8 years. The group included 15 Hindus, 14 Christians and 2 Muslims.

Educational status of mothers showed that 11 had the high school education, 13 had plus 2 education, 5 graduates and 2 postgraduates; 19 (63%) belonged to the middle class and 12 (38.5%) belonged to the lower class socioeconomic strata on the Modified Kuppaswamy scale (2014).

Variable	Plo Living	N	Mean Rank	Sum of Ranks	Mann-Whitney U
QoL overall and General Health	Urban	6	13.42	80.50	59.500
	Rural	25	16.62	415.50	
	Total	31			
QoL-D1 Physical Health	Urban	6	11.50	69.00	48.000
	Rural	25	17.08	427.00	
	Total	31			
QoL-D2 Psychological	Urban	6	7.75	46.50	25.500**
	Rural	25	17.98	449.50	
	Total	31			
QoL-D3 Social	Urban	6	9.50	57.00	36.000*
	Rural	25	17.56	439.00	
	Total	31			

Relationship	Total	31			
QoL-D4 Environment	Urban	6	14.00	84.00	63.000
	Rural	25	16.48	412.00	
	Total	31			

Table 1. Table showing the QoL Scores in Relation to the Place of Living

**Significant at 0.01 levels, *Significant at 0.05 levels.

The overall QoL score on WHO-QOL BREF ranged from 25 - 100 with a mean 52.82 ± 15.38 . Mean QoL scores for the domains physical health, psychological, social relationship and environment were 57.77, 54.68, 61.32 and 50.29, respectively. The participant mothers thus reported a medium quality of life on the WHO QOL rating on a scale of 0 - 100. Mean QoL ranks were high in all domains in the rural population (Table 1). However, QoL scores for psychological (D2) and social relationship (D3) domains showed significant difference in the rural group. The Mann-Whitney U values for psychological domains were 25.500 (Significant at 0.01 levels) and social relationship domain was 36.000 (Significant at 0.05 levels). Family history of developmental delay was obtained in three cases. But there was no history of Down syndrome in close relatives in any of the families. Mean ranks for QoL scores in the environmental domains were significantly high for family history of developmental delay.

Variable	ToF	N	Mean Rank	Sum of Ranks	Mann-Whitney U
QoL Overall and General Health	Nuclear	9	14.61	131.50	86.500
	Joint	22	16.57	364.50	
	Total	31			
QoL-D1 Physical Health	Nuclear	9	13.56	122.00	77.000
	Joint	22	17.00	374.00	
	Total	31			
QoL-D2 Psychological	Nuclear	9	10.06	90.50	45.500*
	Joint	22	18.43	405.50	
	Total	31			
QoL-D3 Social Relationship	Nuclear	9	12.17	109.50	64.500
	Joint	22	17.57	386.50	
	Total	31			
QoL-D4 Environment	Nuclear	9	13.33	120.00	75.000
	Joint	22	17.09	376.00	
	Total	31			

Table 2. QoL and Type of Family

*Significant at 0.05 levels.

The QoL of mothers in relation to the type of family (Table 2) showed that mean rank was higher for the joint family group in all domains. Mann-Whitney U of Psychological domain was 45.500 significant at 0.05 levels. This difference may be due to the better psychological and social support mothers enjoyed in a joint family setting as compared to the nuclear family.

The QoL scores of mothers and the paternal educational status was studied. The difference was significant with Kruskal-Wallis test value of 8.289 (significant at 0.05 levels) between the low education levels and graduate groups in the overall QoL score. No significant difference was observed in the domains. This study shows that when the educational status of the spouse is higher, mothers reported a low QoL score. However, no significant difference existed between

QoL and maternal educational status. The Kruskal-Wallis test value was not significant at 0.05 levels for all domains.

The relation between maternal QoL and religion showed a statistically significant difference in the QoL score of Psychological domain (D2) only, Kruskal-Wallis test value of 6.101, which was significant at 0.05 levels. Among the groups, difference was more between Hindus and Muslims.

Variable	SES	N	Mean Rank	Kruskal-Wallis Test
QoL Overall and General	UM	6	25.00	8.095*
	LM	13	13.04	
	UL	12	14.71	
	Total	31		
QoL-D1 Physical	UM	6	26.92	11.289**
	LM	13	12.88	
	UL	12	13.92	
	Total	31		
QoL-D2 Psychological	UM	6	22.08	4.996
	LM	13	16.69	
	UL	12	12.21	
	Total	31		
QoL-D3 Social	UM	6	18.75	1.019
	LM	13	14.38	
	UL	12	16.38	
	Total	31		
QoL-D4 Environment	UM	6	22.25	5.558
	LM	13	12.12	
	UL	12	17.08	
	Total	31		

Table 3. QoL and Socioeconomic Status

**Significant at 0.01 levels, *Significant at 0.05 levels.

The socioeconomic status was assessed based on the Modified Kuppaswamy scale (2014) and the study group came under three categories, namely Upper-Middle (UM) class, Lower-Middle (LM) class and Upper-Lower (UL) class. Table 3 shows that the QoL scores were high in all domains in the Upper-Middle class and the difference was significant in the overall and general health (total) as well as Physical health domain (D1) with Kruskal-Wallis test values 8.095 and 11.289 (significant at 0.05 and 0.01 levels, respectively).

The maternal QoL scores did not show significant differences with reference to child related variables as age, sex, birth weight, gestational age or medical illness in the child. However, two children families reported better QoL scores compared to single child families.

DISCUSSION

Intellectual disability in a child is a stress for the family and caregiver and disability assessment studies have shown that mental retardation and other disorders lead to significant socio-occupational dysfunction and impaired quality of life for caregivers.⁵ Another study has revealed that parental application for placement of children with severe impairment was significantly related to high parental stress, low social support and poor family atmosphere.⁶

Studies have reported that parents of children with various developmental disabilities experience heightened stress, overburden and marginalisation in society sense of self blame, tiredness or exhaustion.^{4,5} Commenting that little

attention has been given to the health outcomes of caregivers of developmental disabilities, Talley et al identify caregiving as an issue that must be considered in the context of health (physical and psychological) that vary across the lifespan according to the characteristics and developmental levels of both caregivers and care recipients.⁷ Some forms of physical stress for caregivers are suggested to be more detrimental to health than forms of psychological stress. Caregivers report not getting enough sleep, not participating in exercise, eating regular and nutritious meals and failing to seek medical attention for themselves resulting in clinical depression, isolation from social activities and high stress and low quality of life.⁸ These facts indicate that caregivers require supportive services for their caregiving tasks, but also supportive services to find quality of life and balance in their lives. Research suggests that if the caregiver is healthy, the person being cared for will experience much better care.⁷

Thus, it has been concluded that disability impacts the whole family and the determination of appropriate conceptualisation of family outcomes requires an understanding of the impact of members with disability on family members.

This Involves Three Main Issues-

1. Stress and caregiving burden and quality of life,
2. Impact on family functioning, and
3. Eco-cultural adaptation.⁵

Present study showed that the QoL scores were better in rural families and joint family setting compared to the urban nuclear families. This may be due to the fact that family cohesion and support systems may be better in a rural joint family setting. Presence of multiple family members may reduce the parenting stress of the mother of the disabled child, thereby reporting better quality of life. The QoL scores were better for the upper middle class socioeconomic strata in the study group. This indicates that financial status also influenced the quality of life of the mothers. Low QoL scores were reported when the paternal educational status was high.

Caregiving and its related burden are considered to be an important aspect in determining the quality of life of caregivers.⁹ Quality of life of mothers depends on various factors as education, socioeconomic status, family outlook, psychological factors, stress and coping strategies. Support from the spouse and family members is also important for the mother to cope with the psychological and physical stress in bringing up a disabled child. Present study did not assess the stress levels or coping strategies of these mothers. Knowledge and attitude of mothers also need to be studied. Better support systems and improving the awareness of mothers to anticipate medical issues and seek early medical aid can reduce the disease related morbidity of the children, thereby enjoying better quality of life.¹⁰

Parents are major contributors to the development of their children. There is a need to address the burden and psychiatric comorbidity in mothers who are the caregivers to enhance their caregiving ability. There are various psychological measures with proven efficacy that can be directed at caregivers to improve their coping ability. Parent training and education about the nature of disabilities in their children, behavioural problems and future requirements can

help increase their coping mechanisms to manage this chronic stress.^{11,12}

Quality of life of the caregiver also depends on the functional ability of the child. Down syndrome being a condition with significant intellectual disability, QoL of the mother as well as her psychological wellbeing is largely dependent on the functional status and intellectual ability of the child. This aspect needs to be studied further.

CONCLUSION

Medium Quality of Life was reported by most of the mothers of children with Down Syndrome. QOL scores were better in rural joint families and upper middle class families. The maternal QoL scores did not show significant differences with reference to child related variables as age, sex, birth weight, gestational age or medical illness in the child.

Contributions

SSV collected the data, conducted the study and prepared the manuscript and will be the guarantor of the paper, PTB guided the study, gave statistical support and reviewed the manuscript, JMA, BKP and DSM supported the study and critically reviewed the manuscript.

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