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Original Article

Health-related quality of life and coping strategies among families with Down syndrome children in South India

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ABSTRACT

Background: Down Syndrome (DS) is the most common chromosomal disorder associated with intellectual disability. Besides clinical management, additional support to cope with the demands of life is also necessary. These parents are frequently unstable and forego their Quality of Life (QoL), suffer additional economic difficulties, ill health and have lower well-being than families without disabilities. Hence, the study intends to evaluate the Health-Related QoL (HR-QoL) and coping strategies among families of DS children.

Methods: This explorative, cross-sectional study was conducted among parents/caregivers of DS children ($n = 51$). Socio-demographic details, HR-QoL, coping strategies and perspectives on having a child with disability were obtained through a standard questionnaire.

Results: Most DS children were upper and upper-middle class of urban background. The mean score of the QoL of the families was found to be 68.98%. The least and the most affected domains were cognitive functioning (71.67%) and worry (57.33%), respectively. Maximum coping was through the instrumental social support, active coping and religious coping. Though 27.45% were upset with the diagnosis, most had a "feeling of love" towards the child (72.55%). 50.98% had limited knowledge about DS and lacked organizational support (60.78%).

Conclusion: With increasing life expectancy, the gap continues concerning the assessment of needs beyond medical aid among DS children. Better HR-QoL and coping with the stress could be ensured by the provision of comprehensive health policies inclusive of training programs, stress management, as well as psychosocial and organizational support across any socio-economic strata.

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Introduction

Developmental disabilities can be defined as any physical or mental disability that may impair or limit a child's ability to develop cognitively, physically and emotionally. A disabled child's family adjusts on various aspects of life to suit their needs, and the mental and physical stress they undergo impedes their quality of life (QoL).[1] Down's syndrome (DS) is the most common chromosomal disorder associated with moderate to severe mental impairment.[2] The intelligent quotient of an adult with DS is equivalent to an 8 or a 9 year old.[3] According to the World Health Organization, the estimated incidence of DS is between 1 in 1000 and 1 in 1100 live births worldwide and around 1 in 1250 in India.[4]

This syndrome is characterized by dysmorphic features, delayed psychomotor development and associated congenital defects, hypothyroidism, eczema, celiac disease, repeated respiratory infections, and so on, requiring interventions, lifelong surveillance and management.[5] DS children tend to develop slower; therefore require undivided attention and care to foster their development. Although some children can get their schooling in typical schools, most require special setting. This causes tremendous alterations in the lifestyle of the parents and caregivers.[2] Thus, parents need enormous support from family and society to nurture affected child and lead a meaningful life.[6]

The impact of disease on QoL is often underestimated or poorly evaluated in developing countries like India. Although adequate treatment is given at tertiary care setups, the gap exists in the assessment of parental problems and stresses in coping the situation. These parents are more frequently unstable and forego their QoL, suffer from additional economic difficulties, ill health and have lower well-being than families without disabilities.

Coping according to Campbell means an ability to adjust, adapt and meet a challenge successfully.[7] Although some parents do make some behavioural and cognitive efforts to manage the situation, others struggle to bring their life back to normalcy. India with a diverse population has paucity of uniform access to affordable health support system and dedicated one-stop DS multidisciplinary clinics. Consequently, assessment of psychological health of parents and understanding their coping strategies are overshadowed.[8]

The Indian health care system neither has comprehensive policy for DS nor adequate special schools to address the burden. Research on requirements from caregiver perspective would pave way towards recommendations. Hence, the study intends to evaluate the health-related QoL (HR-QoL), coping strategies adopted, perspectives of having an affected child and resources available to the families of children with DS.

Materials and methods

This was an explorative, cross-sectional study conducted at the Centre for Human Genomics and Counselling, JSS Hospital; a tertiary care teaching hospital located in Mysore, Karnataka, India. A convenient sampling technique was used for a duration of 3 months prescribed for the Indian Council of Medical Research-Short Term Studentship (ICMR-STS) study. This included 57 parents/caregivers attending the centre and consenting for the study. Those not living with the child or unable to provide valid details were excluded from the study. The questionnaire was administered to any one parent or immediate caregiver of the DS child, and assistance was provided to those who could not read and write. The questionnaires were also administered orally to the patients in the local language, Kannada, after validation by reliable sources.

The questionnaire-based study included the following components:

a) Socio-demographic details to gather basic information about the parents and their children, including information regarding any co-morbidities, treatments or surgeries undergone.
b) QoL questionnaire: the PedsQL Family Impact Module (FIM) questionnaire was used to assess the impact of chronic medical conditions on the HRQOL of parents and family functioning.[9] The 36-item PedsQL™ FIM is a parent report instrument designed to assess the impact of paediatric chronic health conditions on parents and the family. It includes 6 subscales measuring parents' self-reported functioning: physical functioning (6 items), emotional functioning (5 items), social functioning (4 items), cognitive functioning (5 items), communication (3 items) and worry (5 items); as well as 2 subscales measuring parent-reported family functioning: daily activities (3 items) and family relationships (5 items). The responses are based on a 5-point scale (0–4), with 0 being never a problem and 4 being always a problem. The scoring is reverse, with 0 being 100 and 4 being 0, thus higher scores indicate a better QoL.[10] The necessary permission to use this copyrighted questionnaire was obtained.
c) Coping strategies adapted by the families were gathered through Coping Orientation to Problems Experienced (COPE) inventory questionnaire.[11] It is a 56-item measure that uses a 4-point Likert scale to gather three coping strategies and their associated subscales: problem-focused coping (active coping, planning, instrumental support, and religion scales); active emotional coping (venting, positive reframing, humour, acceptance, and emotional support scales); and avoidant emotional coping (self-distraction, denial, behavioural disengagement, self-blame, and substance use scales). The 4-point Likert scale (1–4) is as follows: 1 = do not do this at all and 4 = do this a lot. The scoring is direct, and various questions are grouped together to form the percentage of coping strategies adapted.[1]
d) Family perspectives on having a child with DS pertaining to the emotions experienced with the diagnosis, feeling towards the child and emotions during disclosure to friends and family; along with the information regarding the resources available to the caregivers were gathered through supplementary expert validated items.

The content validity of the questionnaire was ensured by the two senior subject experts. The same was translated to local language by translator and was retranslated back to English to avoid deviation from theme. The data obtained were

subjected to descriptive and inferential statistics using the SPSS software.

Results

In total, 57 parents/caregivers of DS children were enrolled for the study. Of 57 parents, 55 filled the PedsQL questionnaire, and of 57 parents, 53 filled the COPE inventory questionnaire. The parents who did not fill both the questionnaires were excluded from the study. The socio-demographic characteristics of the study population are described in Table 1.

Our study found that most fathers (51%) and mothers (74.5%) had received secondary or tertiary education. 33.33% of the fathers were skilled workers, whereas most mothers (74.51%) were unemployed and 6 mothers (11.76%) had to leave their job for the extra care of special child. 73% belonged to nuclear families, 84.32% belonged to the upper-middle class and 15.68% belonged to the upper class as per the modified Kuppuswamy classification of socio-economic status (2018). In the present study, 23 DS children (45.1%) had no sibling, 9 had one sibling (17.65%) and 19 had two siblings (37.25%).

QoL questionnaire

The mean score of the QoL of the families was found to be 68.98%. The least and the most affected domains were cognitive functioning (mean −71.67, SD 17.63, p 0.00, z score 1.22) and worry (mean −57.33, SD 13.04, p 0.00, z score −1.91), respectively. Negative Z scores indicate the domains that have impacted most on QoL. Tables 2 and 3 show the mean scores of each domain of QoL assessment and the family demographics affecting the QoL.

COPE inventory questionnaire

Maximum coping was through the use of instrumental social support, active coping, religious coping and positive reinterpretation with Z scores = 1.85, 0.88, 0.82 and 0.66, respectively. Higher Z score indicates that their application is coping with stress. Table 4 shows the mean scores of each parameter of coping assessed using the COPE inventory questionnaire.

There was no significant difference between the coping strategies used by the parents with male and female DS children.

Family perspectives

27.45% of the parents were upset with the diagnosis of DS, followed by 23.53% having mixed feelings (23.53%). Most of the

Table 1 – Socio-demographic characteristics of the study population (n = 51).

Age of the child	1–3	12 (23.53%)	*Parents' occupation*		
	4–6	**23 (45.10%)**	*Father*	Unemployed	0 (0%)
	7–9	6 (11.76%)		Unskilled	3 (5.88%)
	10–12	8 (15.69%)		Semiskilled	12 (23.53%)
	13–15	2 (3.92%)		**Skilled**	**17 (33.33%)**
Sex of the child	**Male**	**32 (62.74%)**		Clerical/Farmer	2 (3.92%)
	Female	19 (37.26%)		Semi-professional	9 (17.65%)
Religion	**Hindu**	**42 (82.35%)**		Professional	8 (15.69%)
	Muslim	7 (13.73%)	*Mother*	**Unemployed**	**38(74.51%)**
	Christian	1 (1.96%)		Unskilled	1 (1.96%)
	Buddhist	1 (1.96%)		Semiskilled	1 (1.96%)
Residence	**Urban**	**33 (64.70%)**		Skilled	1 (1.96%)
	Rural	18 (35.30%)		Clerical/Farmer	0 (0%)
Parents' age				Semi-professional	2 (3.92%)
Father	30–34	11 (21.57%)		Professional	8 (15.69%)
	35–39	**21 (41.18%)**	*Type of family*	Joint	14 (27.45%)
	40–44	17 (33.33%)		**Nuclear**	**37(72.55%)**
	45–49	2 (3.92%)	*Income/capita/month*	0–1999	5 (9.80%)
Mother	20–24	6 (11.76%)		**2000–3999**	**19(37.25%)**
	25–29	15 (29.41%)		4000–5999	9 (17.65%)
	30–34	13 (25.50%)		6000–7999	4 (7.84%)
	35–39	**17 (33.33%)**		8000–9999	2 (3.92%)
Parents' education				10,000–11,999	2 (3.92%)
Father	Primary	5 (9.8%)		12,000–13,999	2 (3.92%)
	Secondary	**13 (25.5%)**		>14,000	8 (15.69%)
	Tertiary	**13 (25.5%)**	*Socio-economic status*	Upper	8 (15.68%)
	Bachelors	10 (19.6%)		**Upper-middle**	**43(84.32%)**
	Masters/Doctoral	10 (19.6%)	*Co-morbidities*	0	31 (60.78%)
Mother	Primary	1 (2.0%)		1	10 (19.61%)
	Secondary	**18 (35.3%)**		2	7 (13.73%)
	Tertiary	**20 (39.2%)**		3	1 (1.96%)
	Bachelors	2 (3.9%)		4	2 (3.92%)
	Masters/Doctoral	10 (19.6%)			

The bold data indicates the variable with the maximum percentage.

Table 2 – Domain-wise distribution of the PedsQL-based HR-QoL of families of DS children (average total score = 68.98, $n = 51$).

Subscale	Mean	Standard deviation	t	Significance (2-tailed)	Mean difference	Z scores
Physical functioning	68.62	20.64	−10.86	<0.001	−31.38	0.554
Emotional functioning	66.33	16.73	−14.37	<0.001	−33.67	0.055
Social functioning	64.71	27.28	−9.24	<0.001	−35.30	-0.300
Cognitive functioning	71.67	17.63	−11.48	<0.001	−28.33	1.219
Communication	63.88	19.70	−13.09	<0.001	−36.12	-0.479
Worry	57.33	13.05	−23.36	<0.001	−42.67	−1.909
Daily activities	65.03	19.72	−12.66	<0.001	−34.97	-0.230
Family relationships	71.08	21.24	−9.72	<0.001	−28.92	1.091

Table 3 – HR-QoL with respect to family demographics ($n = 51$).

Fathers' age (in years)	QoL score	Number of children in the family	QoL score
30–35	52.64	1	65.35
35–40	73.57	2	70.96
40–45	74.01	3	71.18
45–50	66.67	**Socioeconomic status**	**QoL score**
Mothers age (in years)	**QoL score**	Upper class	59.92
20–25	62.92	Upper-middle class	70.20
25–30	61.27	**Co-morbidities**	**QoL score**
30–35	73.04	0	73.78
35–40	73.71	1	69.22
Order of birth	**QoL**	2	64.12
1	68.21	3	63.84
2	69.44	4	62.34

parents had a "feeling of love" towards the child (72.55%). The family's emotions on disclosure of the child's condition were mostly found to be indifferent (41.18%). 26 families had limited knowledge about DS (50.98%) and only 3 families (5.88%) had a good amount of information on DS. Although most families had financial support (72.55%), family backing (88.24%) and caregivers for the child at home (66.67%), they lacked organizational support (60.78%).

Discussion

The presence of a child with DS in the family requires lots of adjustments by the parents and other family members. Although the unmet needs of these parents are universally linked to stress in general, there could be certain specific factors that directly impact parents and their QoL.

Our study had DS children aged up to 15 years with a male preponderance. 65% of families belonged to the urban upper-middle-class society, probably due to accessibility and utility of a tertiary care hospital setup by these strata of society in the study population. Few studies have reported that lower socio-economic status is associated with more stress (environment domain had the lowest scores) because of fewer resources.[1] But another study has deduced that parents of upper socio-economic strata (36.4%) and skilled occupations (43.6%) had more parenting stress, perhaps because of a wider gap between their expectations and reality. This emphasizes the stress for formal and informal social resources to all parents of disabled children irrespective of occupation and socio-economic status, to help them cope.[12] The rural mothers had relatively lower education and income levels [ρ (161) = 0.28 and 0.23, respectively] when compared with the urban background. These factors must be taken into account while prioritizing the health care provisions.[13] Although there was no significant difference in coping strategies among parents of male or female children,

Table 4 – Individual coping strategies adapted using the COPE inventory questionnaire ($n = 51$).

Strategy adopted	Mean	Standard deviation	t	Significance (2-tailed)	Mean difference	Z scores
Positive reinterpretation and growth	2.54	0.696	−15.016	<0.001	−1.46	0.666
Mental disengagement	1.74	0.459	−35.207	<0.001	−2.26	−1.096
Focus on and venting of emotions	2.22	0.619	−20.602	<0.001	−1.78	−0.039
Use of instrumental social support	2.53	0.595	−17.648	<0.001	−1.47	0.652
Active coping	2.24	0.513	−24.550	<0.001	−1.76	0.005
Denial	1.86	0.574	−26.650	<0.001	−2.14	-0.830
Religious coping	3.07	0.551	−12.029	<0.001	-0.93	**1.846**
Humour	1.80	0.614	−25.581	<0.001	−2.20	−0.956
Behavioural disengagement	2.04	0.438	−31.897	<0.001	−1.96	−0.416
Restraint	2.20	0.541	−23.753	<0.001	−1.80	−0.071
Use of emotional social support	2.63	0.451	−21.657	<0.001	−1.37	**0.879**
Substance use	1.22	0.471	−42.163	<0.001	−2.78	−2.229
Acceptance	2.61	0.534	−18.602	<0.001	−1.39	**0.825**
Suppression of competing activities	2.36	0.650	−18.028	<0.001	−1.64	0.274
Planning	2.46	0.481	−22.906	<0.001	−1.54	0.490

The bold data indicates the most common coping strategy adapted by parents (Higher Z Score indicates their utmost usage in coping stress).

gender might play a significant role in the Indian context. In certain parts of India, the female child with a disability is undesirable to parents than a male because of possible neglect and abuse. Female sex has been associated with higher stress ($t = 2.55$, significance $= 0.014$) due to short of expectations from the child to meet parent's expectations and their satisfaction in the parenting role.[12] The type of family may also have an impact on the atmosphere in which children grow. The nuclear families had higher health satisfaction than those in extended families (78.2 for nuclear families vs. 66.9 for extended families, $P < 0.05$), may be due to cultural effects. Probably, this may help to make easy adjustments to intellectual disability as they grow.[14] The magnitudes of early intervention are influenced by various aspects, including parental sociodemographic characteristics that might indirectly influence family outcome, necessitating the need for this data collection.[15]

Parents of children with disabilities seem to exhibit a higher burden and significant impairment in their QoL. The study by Chan et al. among Malaysian mothers found that nearly half of them perceived their QOL as neither poor nor good. The highest and lowest domain scores were found for social relationship (mean = 14.9 ± 2.1) and environmental support (mean = 13.3 ± 2.1), respectively.[13] Our study found that worry (z score = −1.92) and communication (z score = −0.48) had lowest mean scores followed by social functioning (z score = −1.92) and daily activities; perhaps due to lack of social and government support besides stigma attached to disability.[1] As a result, marriages and parenting relationships (22% divorce rate) with specially abled children are taxing.[16] Empathetic family relationships, favourable environment, community awareness and interaction, boost the QoL, thus impact the development.[17,18]

Although socio-demographics influence, psychosocial parameters and child functioning are coherently related to HRQoL. Those related to social support and time pressure need to be addressed particularly. Systematic screenings of parents to detect problems at an early stage are recommended. Sustainable programs and interventions through supportive network should be developed to adapt to individual changing needs and safeguard parents from the stress.[19,20] Our study found that the QoL of families was higher in parents who were neither too young, nor old (35–45 years), which is probably due to the availability of enough resources, and energy to this tier of the society compared with the others.[14] In the study done by Abassi et al., a slight increase in the QoL of families (2 children: mean = 46.93, SD = 8.41; 3 children: mean = 46.87, SD = 8.26) with more than one child was observed.[21] Our study shows consistency with the above results and as the order of the birth of the DS child increased, the QoL improved. Presence of normal children can foster collective responsibilities and provide a sense of security to parents.[1] The QoL was comparatively higher in upper-middle-class families than the upper class (Table 3). Probably the upper-middle-class families tried to accept the affected child as just another normal child, whereas the upper class families lacked emotional connection with them.[12] Our study showed that the QoL of the families decreased with increase in co-morbidities in the child. This accounts to the extra burden of hospital stay, and expenditures borne due to co-morbidities. These children face brunt of disease per se, negatively pronounced family impacts and greater unmet needs. Fostering the establishment and usage of medical homes at the practice level may help alleviate these issues.[22,23]

Comparable to Ganjiwale et al., problem focused coping (active coping, planning, instrumental support and religious scales) was the major strategy used by the parents of disabled children in our study.[1] Many researchers from India have reported that people often find relief in religious propitiation when faced with intractable disease and disability.[10]

Parents from religious background use both theological and medical justifications for their child's disability to provide reasonable description; incorporate spiritual sermon, cultural conviction and individualistic social experiences into coping processes.[24,25]

Parents attributed their progressive growth in confidence, efficient utilization of confronting approaches; rising attention towards health to essential backing from family especially spouse.[26] Although parents experience struggles and challenges, their children bring them much joy and many rewards.[27] Although parents may survive with lost desires, constructive adjustments can occur by the way of altered viewpoints concerning life and disability over time.[28]

Skotko et al. in their inquiry into parent outlooks reported that 99% loved their child, 97% were pleased to have them, 79% acquired an optimistic attitude towards life because of them, 5% suffered discomfiture and 4% expressed grief in having them.[27]

Parents in our study, though experienced initial upset, indifference and anxiousness with the diagnosis gradually developed fondness as the days progressed. Review by Cuskelly et al. has concluded that family life is likely to experience the blend of hassles and uplifts, disappointments and greater satisfaction. Parents associate enfranchisement, self-development and reprioritization, as constructive transformations in parenting DS child.[29]

41% felt indifferent and 25.5% felt sad during disclosure to family. Typically, parents are disappointed initially but positive improvements in the QoL occur with family acceptance and support overtime.[30,31] After birth of affected child, parents initially tend to remain silent, during which feelings such as anger, sadness and discomfort may arise. The turmoil stems from a combination of increased caring needs due to atypical development, along with the family's emotional reactions to the disability.[32] Clarification on ailment, psychosocial support and provision of relevant healthcare helps to overcome barriers, bringing parents closer to their child.[2] Our study showed that most parents had limited or no knowledge about the condition: cause, manifestations and effective management. The study by King et al. concluded that the provision of an advance understanding of the changes in beliefs that they might undergo fosters better coping. This might assist service providers in delivering individualized and family-centred services to families.[28]

Most children had no associated co-morbidities or were suffering from one or two of them. The life expectancy in DS has improved dramatically off late because of the availability of treatment for associated co-morbidities.[33] Hence, the health care services must be planned considering the life expectancy and changing needs with age.

In Italy, inclusive teaching and social integration is followed to consider them in milieu with their peers. But this has not warranted a satisfactory QoL in adulthood due to variability of performance demanding case-specific options in terms of work, living arrangements, social networking and medical services.[34] The healthcare is usually often centred towards the affected child resulting in the development of fear, guilt, frustration, uncertainty, anger, sadness, loss and chronic fatigue. Thus, the psychosocial factors and interpersonal relationships for the caregivers must be incorporated into any interventions.[35] The journey of parents begins with diagnosis, prenatally or at birth, and early interactions prime the family for acceptance along preparation for critical gateways to medical and developmental services. A co-ordinated system should provide the best medical and developmental care, information and family support throughout the lifespan.[36] Currently, these services are unorganised with meagre financial support, resulting in a heavy toll on these families.[37] Formal early intervention programs strengthen not only children's intellectual and adaptive functioning, but also the family's functioning, interactions, social support networks fostering positive parental attitudes, and family functioning, conducive to child development and behaviour.[38,39] Psychoeducational training programs focused on reducing parental stress, training mothers to parent under stress, family counselling to improve psychological well-being and effective coping strategies are worthwhile.[40]

Lastly, distinguishing and focussing the disparities in medically underserved geographical areas and populaces will ensure that smaller number of families get bogged down.

Limitations

Involvement of cases attending the hospital would underestimate the prevalence of this syndrome. Inclusion of cases from grass root level would be ideal. Statistical correlation between the co-morbidities and the QoL could not be ascertained because of the smaller sample size. The results cannot be generalized because of the sampling technique and absence of prior sample size calculation.

Conclusion

Down Syndrome is a condition with an intellectual disability requiring early intervention, lifelong provision of care and support. The HR-QoL is dependent on the parental age, number of children and associated co-morbidities. Worry and communication domains were most affected; family relationship and cognitive functioning were conducive to better QoL. Religious coping, acceptance and emotional social support were foremost coping strategies. The need of the hour is to provide flexible, efficient health care providers at every stratum of society. Newer health policies inclusive of psychosocial support, training programs, stress management through a coordinated system could ensure better HR-QoL and effective coping. This would safeguard the children with disability, thus warrant a better QoL and standard of living for their families.

Ethical clearance

Institutional ethical clearance was obtained (IEC letter no JSSMC/IEC/3107/15STS/2018-19. Dated 1st July 2018).

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Disclosure of competing interest

The authors have none to declare.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.mjafi.2020.07.010.

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