

Original Article

Health Related Quality of Life of Under Five Children with Down Syndrome and Sociodemographic Correlates

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Abstract

Background: Many researchers have revealed that health related quality of life (HRQOL) is significantly related to multiple socio-demographic factors in the general population. Only one previous research examined HRQOL in under five children with Down Syndrome (DS). So far, there are no DS-specific or gold standard tools present for this purpose.

Objective(s): This study aimed to measure HRQOL in under five children with DS and to investigate its relation to some socio-demographic characteristics of under 5 children with DS and their caregivers.

Methods: In a cross-sectional study of 267 under five children with DS, HRQOL was measured with the TNO-AZL Preschool Children Quality of Life (TAPQOL) questionnaire. TAPQOL was translated into Arabic and validated. Sociodemographic data were collected through a validated pre-designed structured interview questionnaire filled by the caregivers (mostly mothers).

Results: The study revealed that 59.6%, 37.1% and 3.4% of the studied children had good, fair and poor HRQOL, respectively. Good HRQOL were significantly associated with children age group (1-<1.5 years) (0.000), mothers' age group (<20 years) (0.039), professional work of the father (0.000) and married parents (0.042). These results were statistically significant. Nearly two thirds (62.5%) of the studied children with average socioeconomic status, had good HRQOL. This result was not statistically significant.

Conclusion: More than half of the studied sample had good HRQOL. Good HRQOL were significantly associated with children age group (1-<1.5 years), mothers' age group (<20 years), professional work of the father and married parents. The relation between the HRQOL and the socioeconomic class was not significant.

Keywords: Down syndrome; HRQOL; TAPQOL questionnaire

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INTRODUCTION

Down syndrome (DS) is the most common genetic cause of intellectual disability, ⁽¹⁾ with an incidence of 1 in 650–1000 of annual live births worldwide. ⁽²⁾ Children with DS suffer from several malformations and medical problems, ⁽³⁾ due to the presence of all or part of a third copy of chromosome 21. ⁽⁴⁾ Individuals with DS suffer difficulties in learning, memory and language capabilities that cause difficulties in adaptive behavior. ⁽⁴⁾ The World Health Organization (WHO) refers to health related quality of life (HRQOL) as a multidimensional concept consisting at least of physical, psychological and social domains. ⁽⁵⁾ Taillefer et al., ⁽⁶⁾ describe HRQOL covering physical,

emotional, cognitive, social and behavioral components of well-being and function as perceived by patients and/or other observers related to the patient's health state.

Only a few of research studied HRQOL in DS, and till now, there are no DS-specific or gold standard tools present for this purpose. ⁽⁷⁾ Most of the few present research in this issue has shown that both children and adults with DS experience poorer HRQOL than typically developing individuals without DS. ⁽⁸⁾ One study, however, shows that adults with DS in the United States (US) experience better than average HRQOL. ⁽⁹⁾

A lot of studies have reported multiple socio-demographic factors, such as age, gender, education, the person's income, ⁽¹⁰⁾ and marital status ⁽¹¹⁾ to be

significantly associated with HRQOL. These relationships between socio-demographic aspects and HRQOL were searched intensively in general populations worldwide.⁽¹²⁾ Yet, a few studies were conducted regarding this issue in under five children with DS, hence, there is a shortage in evidence regarding the socio-demographic determinants of HRQOL amongst under five children with DS. The current study was carried out to measure the HRQOL of under 5 children with DS and to determine its relation to some socio-demographic characteristics of these children and their caregivers.

METHODS

A cross-sectional study was conducted among under 5 children with DS, attending genetics clinic in Alexandria University Children Hospital (Smouha) and their caregivers (mostly mothers). Two hundred sixty-seven [this sample size was calculated using Open Epi program assuming degree of precision 6% and suggested frequency of poor HRQOL 50%] children with DS (diagnosed by chromosomal analysis) were included in the study. All eligible children to be included in the study were recruited until the calculated sample size was fulfilled. A pre-designed structured interviewing questionnaire was used to collect socio-demographic data and this questionnaire included: **Parents' data:** age, education, occupation, marital status, consanguinity and attending counselling sessions. **Caregivers' data (other than parents):** age, education, occupation, marital status, living of the child with him/ her, the number of times he/ she see the child with DS, attending counselling sessions. **Child's data:** age, sex, going to nursery or kindergarten, care provider. **Housing conditions data (socioeconomic status):** computer use, per capita income, family size, crowding index, sewage and waste disposal. Socio-demographic items were tested for face validity by five expert judges. A socioeconomic score was calculated based on socioeconomic scale updated by Fahmy et al.⁽¹³⁾

The Netherlands Organization for Applied Scientific Research Academic Medical Center (TNO-AZL) Preschool children Quality of Life (TAPQOL) scale was used to describe the HRQOL of sampled children. This is a generic instrument consisting of 43 items, including four domains covering physical, social, cognitive and emotional functioning in preschool children aged 2 to 48 months. The number of items per scale ranges from three to seven. It measures parent's perception of HRQOL, defined as health status in 12 scales weighted by the impact of the health status problems on well-being. There are 6 scales with 20 items in the physical functioning domain [sleeping scale (4 items: item #1- item#4),

appetite scale (3 items: item #5- item #7), lungs (3 items: item #8- item #10), stomach (3 items: item #11- item #13), skin (3 items: item #14- item #16) and motor functioning (4 items: item #17- item #20)]. There are 2 scales with 10 items in the social functioning domain [social functioning scale (3 items: item #21- item #23) and problem behavior scale (7 items: item #24- item #30)]. There is one scale with 4 items in the cognitive functioning domain [communication scale (4 items: item #31- item #34)]. There are 3 scales with 9 items in the emotional functioning domain [Anxiety (3 items: item #35- item #37), positive mood (3 items: item #38- item #40) and liveliness (3 items: item #41- item #43)]. For seven TAPQOL scales (sleeping, appetite, lungs, stomach, skin, motor functioning, communication), items consist of two questions. In these items (item #1- item #20 and item #31- item#34), the first question of the item records the frequency of a specific complaint or limitation as "never", "occasionally" or "often". Reply of "never" is scored as "4". If such a problem is reported (i.e., the reply of the first question is "occasionally" or "often"), then the second question of the item assesses the well-being of the child in relation to this problem as "fine", "not so good", "quite bad" and "bad". Replies of "fine", "not so good", "quite bad" and "bad" are scored as "3", "2", "1" and "0" respectively. For the other five TAPQOL scales (social functioning, problem behavior, anxiety, positive mood and liveliness) items (item #21- item #30 and item #35- item #43) consist of only the aforementioned first question of the item but with different scoring; "2" for "never", "1" for "occasionally" and "0" for "often". TAPQOL items generally relate to the past three months. The scales measuring motor functioning, social functioning and cognitive functioning are applicable only to children one and half years and older, because these scales relate to age-specific complications that are not applicable to children younger than 1.5 years. Scale scores were gained by adding item scores within scales and modifying crude scale scores linearly to a 0-100 scale i.e., making the maximum possible TAPQOL score for children of both age groups (<1.5 and ≥ 1.5 years) the same (100) in spite of the different number of scales answered with each age group of them. This allowed calculating the percent mean score of the overall quality of life for both age groups together with higher scores indicating better QOL.

The reliability and discriminative validity of its scales, in Dutch, for infants as well as toddlers was reported satisfactory⁽¹⁴⁾. The English version of the TAPQOL, translated from Dutch in accordance with international guidelines,⁽¹⁵⁾ is available. The English TAPQOL scale was translated into Arabic by the researcher and the translation was tested for validity

by 8 experts.

As regards the statistical analysis, the collected data were fed to the computer and analyzed using IBM SPSS software package version 20.0. ⁽¹⁶⁾ Qualitative data were described using number and percent. Quantitative data were described using mean and standard deviation. Significance of the obtained results was judged at the 5% level. The used tests were Monte Carlo test, F-test (ANOVA) and Post Hoc test (LSD).

Ethical considerations: This study was approved by the Ethics Committee of the High Institute of Public Health, Alexandria University. The study conformed to the International Guidelines for Research Ethics. An informed verbal consent was obtained from each caregiver who agreed to participate in the study after explanation of the purposes and benefits of research. Confidentiality of information, and anonymity were guaranteed and maintained.

RESULTS

The socio-demographic characteristics of the selected children with DS and their caregivers are shown in table 1 and figure 1. It appears from table 1 that the mean age of the sampled children was 17.69 ± 14.61 months, most of them were males (54.7%). The majority (91.0%) of the studied sample did not go to any educational place.

Mother and father together were the caregivers for most of the studied sample representing 92.1%, with history of non-consanguineous marriages among the great proportion of them (80.9%).

Concerning the maternal and father's data, table 1 illustrates that the mean age of the mothers and fathers of the studied sample were (34.86 ± 7.47) and (40.22 ± 9.63) years, respectively. The great proportion (87.6%) of the mothers of the studied sample were housewives and more than one third (35.2%) completed secondary school or diploma as an educational level. Also, nearly one third (31.8%) of fathers of the studied sample were of the same educational level of the mothers, and (34.1%) were manual workers. Regarding the marital status of the parents, the majority (92.1%) were married.

Figure 1 displays the socioeconomic status of the studied sample. Using the overall socioeconomic scores, nearly half of the families (44.9%) were of average socioeconomic level.

Table 2 shows the mean scores of the TAPQOL scale among the studied sample and the distribution of the studied sample according to the TAPQOL scale scores.

The table reveals that the percent mean score of the sampled children as regards the overall quality of life was $77.16 \pm 12.95\%$.

Concerning physical functioning domain, the percent mean score of the sampled children was 74.44 ± 14.91 . The percent mean score of the sampled children as regards sleeping, appetite, lungs, stomach, skin and motor function scales were 79.92 ± 21.97 , 71.97 ± 32.38 , 74.53 ± 28.66 , 68.98 ± 25.28 , 91.64 ± 13.04 , 35.36 ± 5.08 , respectively.

As regards social functioning domain, the percent mean score of the sampled children was 71.52 ± 16.72 . Regarding the social functioning and problem behavior scales, the percent mean score of the sampled children were 94.12 ± 15.67 , 61.84 ± 20.04 , respectively.

Regarding the cognitive functioning domain (communication scale), the percent mean score of the sampled children was 47.98 ± 12.87 .

Concerning emotional functioning domain, the percent mean score of the sampled children was 85.70 ± 14.15 . As regards anxiety, positive mood and liveliness, the mean% score of the sampled children were 67.17 ± 29.82 , 95.51 ± 13.66 , 94.32 ± 13.71 , respectively.

The table also shows that more than half of the sampled children (59.6%) had good HRQOL. More than one third of the sampled children (37.1%) had fair HRQOL. Only 3.4% of the sampled children had poor HRQOL.

More than half (55.8%) of the sampled children had good HRQOL as regards physical functioning. Three fourths of the sampled children (75.3%) had good HRQOL as regards sleeping. As regards lungs, more than half (55.1%) of the sampled children had good HRQOL and near one third of the sampled children (30.3%) had fair HRQOL. The majority (89.9%) of the sampled children had good HRQOL as regards skin. Nearly two thirds (64.8%) of the sampled children had poor HRQOL as regards motor functioning.

Nearly one-half (51.4%) of the sampled children had good HRQOL as regards social functioning domain. While, the great proportion of the sampled children (85.7%) had good HRQOL as regards social functioning scale. About half (50.5%) of the sampled children had fair HRQOL as regards problem behavior.

Most (84.3%) of the sampled children had good HRQOL as regards emotional functioning. Near half of the sampled children (47.6%) had good HRQOL as regards anxiety and (92.1%) had good HRQOL as regards positive mood and the same percentage exactly (92.1%) had good HRQOL as regards liveliness.

Table (1): Distribution of the preschool Down syndrome children according to socio-demographic data

Socio-demographic items		Preschool Down Syndrome Children (n=267)	
		No.	%
A) Child's characteristics			
1) Age (Months)	<ul style="list-style-type: none"> • 2- <6 months • 6 months - <1 year • 1 - <1.5 years • 1.5 - <2 years • 2 - <4 years 	57 81 24 31 74	21.3 30.3 9.0 11.6 27.7
	Mean ± SD.	17.69 ± 14.61	
2) Sex	<ul style="list-style-type: none"> • Male • Female 	146 121	54.7 45.3
3) Educational place	<ul style="list-style-type: none"> • Nursery • Kindergarten • No place 	21 3 243	7.9 1.1 91.0
4) Care provider	<ul style="list-style-type: none"> • Both mother and father • Only mother • Only father • Grandfather • Grandmother • Uncle or Aunt / father 	246 12 3 6 9 3	92.1 4.4 1.1 2.2 3.4 1.1
B) Family-related characteristics			
(a) Mothers' characteristics			
1) Age in years	<ul style="list-style-type: none"> • <20 • 20 - <30 • 30 - <40 • ≥ 40 	3 66 102 96	1.1 24.7 38.2 36.0
	Mean ± SD.	34.86 ± 7.47	
2) Work	<ul style="list-style-type: none"> • Do not work • Work 	234 33	87.6 12.4
3) Education	<ul style="list-style-type: none"> • Illiterate or read and write. • Primary and preparatory school • Secondary school/ diploma. • Institute & University 	52 63 94 58	19.5 23.6 35.2 21.7
(b) Fathers' characteristics			
1) Age (years)	<ul style="list-style-type: none"> • 20 - <30 • 30 - <40 • 40 - <50 • ≥ 50 	33 103 83 48	12.4 38.5 31.1 18.0
	Mean ± SD.	40.22 ± 9.63	
2) Occupation	<ul style="list-style-type: none"> • Not working • Pension • Manual • Literal • Trading • Clerk • Professional (professor, doctor, engineer, teacher, lawyer, accountant ...etc.) • Others 	18 6 91 46 21 39 37 9	6.7 2.2 34.1 17.2 7.9 14.6 13.9 3.4
3) Education	<ul style="list-style-type: none"> • Illiterate& read and write • Primary& preparatory school • Secondary school/ diploma. • Institute& university 	73 48 85 61	27.3 17.9 31.8 23
(c) Marital status	<ul style="list-style-type: none"> • Separated • Divorced • Married 	9 12 246	3.4 4. 92.1
(d) Consanguinity	<ul style="list-style-type: none"> • No • Yes 	216 51	80.9 19.1

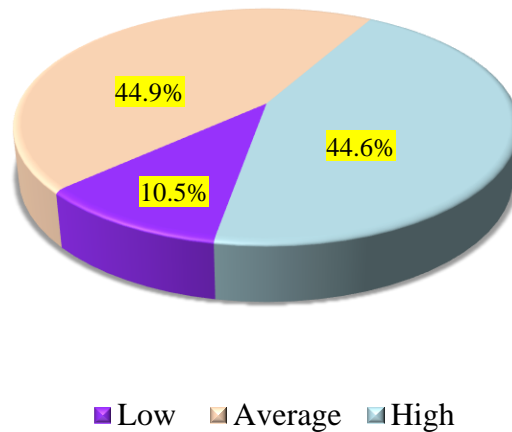


Figure (1): Distribution of the preschool Down syndrome children according to socioeconomic class

Table (2): Distribution of the preschool Down syndrome children according to the TAPQOL scale scores and HRQOL of different domains

TAPQOL domains	Percent mean score \pm SD	HRQOL					
		<50% Poor		50 - <75% Fair		\geq 75% Good	
		No.	%	No.	%	No.	%
Physical functioning	74.44 \pm 14.91	15	5.6	103	38.6	149	55.8
Sleeping	79.92 \pm 21.97	21	7.9	45	16.9	201	75.3
Appetite	71.97 \pm 32.38	60	22.5	56	21.0	151	56.6
Lungs	74.53 \pm 28.66	39	14.6	81	30.3	147	55.1
Stomach	68.98 \pm 25.28	39	14.6	119	44.6	109	40.8
Skin	91.64 \pm 13.04	3	1.1	24	9.0	240	89.9
Motor functioning (n = 105)*	35.36 \pm 5.08	68	64.8	15	14.3	22	21.0
Social functioning (n = 105)*	71.52 \pm 16.72	9	8.6	42	40.0	54	51.4
Social functioning (n = 105)*	94.12 \pm 15.67	6	5.7	9	9.6	90	85.7
Problem behavior (n = 105)*	61.84 \pm 20.04	22	21.0	53	50.5	30	28.6
Cognitive functioning (n = 105)*	47.98 \pm 12.87	25	23.8	70	66.7	10	9.5
Communication	47.98 \pm 12.87	25	23.8	70	66.7	10	9.5
Emotional functioning	85.70 \pm 14.15	6	2.2	36	13.5	225	84.3
Anxiety	67.17 \pm 29.82	30	11.2	110	41.2	127	47.6
Positive mood	95.51 \pm 13.66	6	2.2	15	5.6	246	92.1
Liveliness	94.32 \pm 13.71	3	1.1	18	6.7	246	92.1
Overall HRQOL (n=267)	77.16 \pm 12.95	9	3.4	99	37.1	159	59.6

*Number of children one and half years and older = 105

Table 3: (A) shows the relation between overall TAPQOL scale and socio-demographic data. Regarding child's age, the table portrays that the great proportion (84.2%) and three quarters (75%) of children in the age group (2-< 6 months) (1year-<1.5 years) had good quality of life. The differences were statistically significant ($^{MC}P<0.001$). The table also shows that, 60% and 57.1% of children who attended no or nursery educational place had good quality of life with no significant differences ($^{MC}P=0.222$).

Regarding care-providers, more than half (59.8%) of the sampled children whose care-providers were the mother and the father together, had good HRQOL. This relation was statistically significant ($p= 0.014$). Three-fourth (75%) of the sampled children whose care-provider

was the mother only, had good HRQOL. This relation was also statistically significant ($^{MC}p=0.000$).

According to mother's age, all sampled children belonged to mothers in age group <20 years (100%), had good HRQOL and 67.2% of university educated mothers had also good HRQOL. The relation was statistically significant ($^{MC}P=0.006$ and 0.026 respectively).

The table also illustrates the relation between overall TAPQOL scale and socio-demographic data of the father. Regarding to father's age, near three-quarters (72.7%) of the sampled children belonged to fathers in age group 20-<30 years, had good HRQOL. On the other hand, nearly two-thirds (62.5%) of the sampled children belonged to fathers in age group ≥ 50 years had good HRQOL. These

results were statistically significant ($P=0.019$).

As regards father's occupation, 72.5% of the studied sample whose fathers were manual workers, had good HRQOL, and nearly two-thirds (64.9%) whose fathers were professional workers, had good HRQOL. These differences were statistically significant. ($^{MC}p < 0.001$).

Regarding father's education, more than half of the sampled children belonged to fathers with educational level of illiterate or read and write (57.5%), had good HRQOL. Near three-fourth of the sampled children belonged to fathers with primary or preparatory educational level (75.0%), had good HRQOL. More than half of the sampled children belonged to fathers with educational level of secondary school/ diploma (52.9%),

had good HRQOL. More than half (59.0%) of the sampled children belonged to mothers with university education, had good HRQOL. These differences were statistically significant ($^{MC}p=0.039$).

Regarding marital status, more than two-thirds of the sampled children belonged to separated parents (66.7%), had good HRQOL. Three-fourths of the sampled children belonged to divorced parents (75.0%), had good HRQOL. more than half of the sampled children belonged to married parents (58.5%), had good HRQOL. These differences were statistically significant ($^{MC}p=0.002$).

The relation between overall quality of life and the rest of the socio-demographic data was not statistically significant. ($^{MC}p > 0.05$)

Table (3): (A) Relation between overall TAPQOL scale score and socio-demographic data of preschool Down syndrome children

		Overall HRQOL (n=267)								
Socio-demographic data		Poor (<50%) (n = 9)		Fair (50 - <75%) (n = 99)		Good (≥75%) (n = 159)		p	Mean±SD	F (p)
		No.	%	No.	%	No.	%			
A) Child's characteristics	2-<6 months	0	0.0	9	15.8	48	84.2		84.97±10.84	
	6 months - <1 year	3	3.7	21	25.9	57	70.4	$^{MC}p = <0.001^*$	78.52±12.92	22.223* (0.000) *
	1 - <1.5 years	0	0.0	6	25.0	18	75.0		86.25±10.98	
1) Age (Months)	1.5 - <2 years	0	0.0	19	61.3	12	38.7		70.16±7.53	
2) Care provider	2 - <4 years	6	8.1	44	59.5	24	32.4		69.65±11.05	
	Both mother and father	6	2.4	93	37.80	147	59.8		77.71±12.94	
	Only mother	3	25	0	0	9	75	$^{MC}p = 0.006^*$	70.74±14.95	2.268 (0.081)
	Only father	0	0	3	100	0	0		64.29±0.00	
B) Family-related characteristics	Not mother nor father	0	0	3	50	3	50		74.00±2.19	
	<20	0	0.0	0	0.0	3	100.0		92.00±0.00	
	20 - <30	3	4.5	27	40.9	36	54.5	$^{MC}p = 0.006^*$	75.40±14.20	2.827* (0.039) *
(a) Mothers' characteristics	30 - <40	6	5.9	27	26.5	69	67.6		79.07±14.76	
1) Age in years	≥ 40	0	0.0	45	46.9	51	53.1		75.88±9.25	
2) Education	Illiterate or read and write	6	11.5	16	30.8	30	57.7		73.93±14.88	
(b) Fathers' characteristics	Primary and preparatory school	0	0.0	24	38.1	39	61.9	$^{MC}p = 0.026^*$	77.98±12.26	2.532 (0.058)
	Secondary school/ diploma.	3	3.2	40	42.6	51	54.3		76.40±13.74	
	University	0	0.0	19	32.8	39	67.2		80.41±9.56	
	20 - <30	0	0.0	9	27.3	24	72.7		79.59±13.53	
1) Age (years)	30 - <40	9	8.7	40	38.8	54	52.4	$^{MC}p = 0.019^*$	76.08±15.77	1.291 (0.278)
40 - <50	0	0.0	32	38.6	51	61.4	78.60±9.70			
≥ 50	0	0.0	18	37.5	30	62.5	75.33±10.35			
2) Occupation	Not working	6	33.3	3	16.7	9	50.0		64.62±20.65	
(c) Marital status	Pension	0	0.0	3	50.0	3	50.0		72.65±14.62	
	Manual	0	0.0	25	27.5	66	72.5		79.23±12.12	
	Literal	3	6.5	22	47.8	21	45.7	$^{MC}p = <0.001^*$	75.34±13.76	4.267* (0.000) *
	Trading	0	0.0	9	42.9	12	57.1		75.29±8.23	
	Clerk	0	0.0	21	53.8	18	46.2		76.42±9.58	
	Professional	0	0.0	13	35.1	24	64.9		81.75±10.41	
	Others	0	0.0	3	33.3	6	66.7		82.36±12.37	
	Illiterate & read and write	3	4.1	28	38.4	42	57.5		77.20±14.14	
	Primary school & preparatory schools	3	6.3	9	18.8	36	75.0	$^{MC}p = 0.039^*$	77.05±13.19	1.422 (0.237)
	Secondary school/ diploma.	3	3.5	37	43.5	45	52.9		75.31±12.68	
Institute & university	0	0.0	25	41.0	36	59.0		79.79±11.45		
Separated	3	33.3	0	0.0	6	66.7	$^{MC}p = 0.002^*$	66.84±15.27	3.216* (0.042) *	
Divorced	0	0.0	3	25.0	9	75.0		75.19±7.29		
Married	6	2.4	96	39.0	144	58.5		77.64±12.96		

MC: Monte Carlo

*: Statistically significant at $p \leq 0.05$

Table 3: (A) & (B) reveals that the overall HRQOL was highest for the age group 1-1.5 years (84.97±10.84) and it was lower among age groups 6 months -< 1 year, 1.5 - <2

years and 2- <4 years (78.52±12.92, 70.16±7.53 and 69.65±11.05 respectively). These differences were statistically significant ($F=22.223$, $P=0.000$). The overall

HRQOL for the age group 1-1.5 years is statistically significantly higher than that for age group of 6 months-<1year. (P=0.001). The overall HRQOL score was highest for the children whose care providers are both parents (77.71±12.94). These differences were statistically insignificant. (F=2.268, P=0.081). The overall HRQOL score was highest for the mothers in the age group <20 years (92.00±0.00). These differences were statistically significant (F=2.827, P=0.039). The overall HRQOL for the mothers in the age group <20 years is statistically significantly higher than that for the mothers in the age groups of 20 - <30 years and ≥ 40 (P=0.029 and 0.033 respectively). The overall HRQOL was highest for university educated mothers (80.41±9.56). These differences were statistically insignificant. (F=2.532, P=0.058). The overall HRQOL score was highest for professional work of the father (81.75±10.41). These differences were statistically significant (F= 4.267, P=0.000). The overall HRQOL score for professional work of the father is statistically significantly higher than for the literal work and for fathers who do not work. (P=0.000 and 0.020 respectively). The overall HRQOL score was highest for the married parents (77.64±12.96) These differences were also statistically significant. (F= 3.216, P=0.042). The overall HRQOL is for married parents is statistically significantly higher than for separated parents. (P= 0.014)

overall HRQOL. Near two-thirds (62.5%) of the sampled children with average socioeconomic status, had good HRQOL. More than half (58.0%) of the sampled children with high socioeconomic status had good HRQOL. The results were not statistically significant (p=0.286).

Table (3): (B) Summary of the significant results of LSD test

Socio-demographic Characteristics	Overall Quality of Life		Sig. of mean difference (I-J)
	(I)	(J)	
A) Child's characteristics 1) Age (Months)	2-<6 months	6 months - <1 year	0.001*
		1.5 - <2 years	0.000*
	6 months - <1 year	2 - <4 years	0.000*
		1 - <1.5 years	0.003*
B) Family-related characteristics	<20	1.5 - <2 years	0.001*
		2 - <4 years	0.000*
(a) Mothers' characteristics 1) Age in years	<20	20 - <30	0.029*
		≥ 40	0.033*
(b) Fathers' characteristics 1) Occupation	Not working	Manual	0.000*
		literal	0.002*
		Trading	0.008*
		Clerk	0.001*
(c) Marital status	Separated	Professional	0.000*
		Others	0.001*
	Literal	Professional	0.020*
	Separated	Married	0.014*

Figure 2 shows the relation between TAPQOL scale and socioeconomic status scale. It shows that 53.6% of the sampled children with low socioeconomic status had good

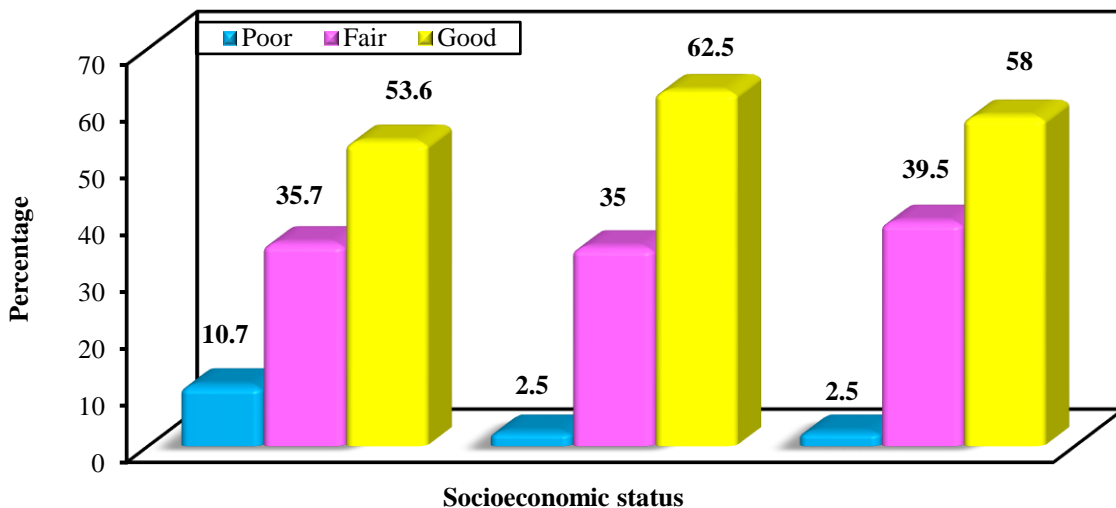


Figure (2): Relation between overall TAPQOL scale scores and socioeconomic class among preschool Down syndrome children

DISCUSSION

A lot of studies focused on the medical aspects of DS, such as congenital defects or organic disorders, for which children with DS are at high risk. ⁽¹⁷⁾

However, to date, there is little research on HRQOL in DS, and existing research is variable with regard to reported HRQOL in DS. ⁽⁷⁾ This study aimed to measure the HRQOL of under 5 children with DS and to determine the relation of HRQOL to some socio-demographic characteristics of these children and their care-givers.

In the current study, the overall percent mean score of the TAPQOL was (77.16±12.95). The higher scores were observed among the emotional functioning domain (85.70±14.15) and physical functioning domain (74.44±14.91) (Table 2).

The findings of the current study have been in agreement with Weijerman et al.,⁽¹⁸⁾ in certain scales as sleeping, lungs, skin, social function, positive mood, anxiety, and liveliness scales, while they have been in contradictory in scales (appetite, stomach, motor function domain, problem behavior and communication).

The findings of the present study [Table 3: (A)] have been in accordance with the findings of Weijerman et al.,⁽¹⁸⁾ regarding the relation of HRQOL to the maternal education. Our findings (Figure 2) have been partially in accordance with Keyvanara et al.,⁽²⁵⁾ regarding the relation of overall HRQOL to overall socioeconomic status scale.

CONCLUSION AND RECOMMENDATIONS

More than half, more than one third and only less than one-twentieth of the studied preschool DS children had good, fair and poor HRQOL, respectively. Good HRQOL were significantly associated with children age group (1-<1.5 years), mothers' age group (<20 years), professional work of the father and married parents. The relation between the HRQOL and the socioeconomic class was not significant. More research and investigations are recommended to measure HRQOL, assess its relation to the socio-demographic characteristics and detect other factors which affect the HRQOL in under five children with DS. It is also recommended to develop a DS-specific instrument for measuring HRQOL in those children and to train the pediatricians and other health care professionals on the application of the HRQOL assessment tool.

CONFLICT OF INTEREST

The authors declare no conflict of interest

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