Health-related quality of life association with sociodemographic characteristics among children under-five with Down syndrome in Western Region Secondary Care Hospitals, Saudi Arabia

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ABSTRACT

Background: The Health-Related Quality of Life (HRQoL) of children with Down syndrome (DS) can be significantly affected by various physical, social, and cognitive elements. There is a scarcity of research on the HROOL of Saudi children and its correlation with sociodemographic factors. Therefore, our objective was to evaluate the HRQoL of children under the age of 5 years with DS in the Western Region of Saudi Arabia. Methods: The study included children under 5 years with DS who were receiving care at secondary care hospitals in Taif, Mecca, and Jeddah. The children were accompanied by their parents or caregivers, who provided sociodemographic and child-specific data as well as medical information. They completed a validated TNO-AZL Preschool Children Quality of Life (TAPQOL) questionnaire. The association between HRQoL and respondents' characteristics was assessed using independent samples t-test, ANOVA, Mann-Whitney, and Kruskal-Wallis tests. A multivariate linear regression analysis was conducted to examine the association between the TAPQOL scores and sociodemographic characteristics in children under the age of 5 years children with DS. Results: A total of 460 responded to the questionnaire. The overall HRQoL score was high. The scores for physical functioning were relatively high, particularly for motor functioning (mean = 86.64) and skin health (mean = 85.68). In addition, social functioning exhibited a lower level, with a significant difference (mean = 25.29). The cognitive functioning scores exhibited variability, with communication scoring relatively high (mean = 76.68), while positive mood (mean = 19.51) and liveliness (mean = 21.25) were significantly low. There was a significant correlation between the educational level and occupation of both fathers and mothers and their HRQoL. Specifically, individuals with higher education and stable employment had better HRQoL scores. Parents' health also has an impact on HRQoL, with children of parents without comorbidities scoring higher. Furthermore, there was a significant association between higher sociodemographic levels of parents and improved HRQoL of the patients. Conclusions: The level of HRQoL among children with DS was high, particularly in the physical and cognitive domains. The sociodemographic factors of parents, specifically the level of education and occupation of fathers, have been identified as essential factors influencing HRQoL. Providing increased economic and educational support for families has a significant positive impact on the quality of life for these children.

Keywords: Health-related quality of life, preschool children, preschool children quality of life, Saudi Arabia, socioeconomic, trisomy 21

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Received: 13-07-2024 **Revised:** 09-08-2024 **Accepted:** 29-08-2024 **Published:** 21-02-2025

Access this article online

Quick Response Code:

Website:

http://journals.lww.com/JFMPC

DOI:

10.4103/jfmpc.jfmpc_1202_24

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How to cite this article: Almalki SR, Alotaibi AW, Albalawi AM, Aloufi ME, El-Fatah NK. Health-related quality of life association with sociodemographic characteristics among children under-five with Down syndrome in Western Region Secondary Care Hospitals, Saudi Arabia. J Family Med Prim Care 2025;14:617-25.

Introduction

Down's syndrome is a widely recognized chromosomal disorder, with an estimated incidence of 1 in 1,000 to 1 in 1,100 live births worldwide. Approximately 3,000 to 5,000 children are born with this chromosome disorder on an annual basis.^[1] The prevalence of DS in certain Arab countries exceeds 12 to 17 per 10,000, which is the average rate observed in industrialized countries.^[2] The occurrence of DS in Saudi Arabia has been documented to be 6.6 cases per 10,000 live births.^[3] Down's syndrome is caused by trisomy of chromosome 21, which occurs due to meiotic nondisjunction. Children with DS usually experience intellectual impairments accompanied by multiple comorbidities and diseases. These include various congenital malformations such as heart defects, hematological diseases, hearing and visual impairment, motor and developmental abnormalities, and growth retardation. The presence of these comorbidities and various impairments in DS patients may affect their quality of life. [4-6]

In 1993, WHO defined quality of life as: "An individual's perception of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns." It is a multidimensional concept that encompasses various aspects, such as physical, psychological, and social well-being. Different psychometric tests have been used to measure the HRQoL, such as the generic Pediatric Quality of Life Inventory (PedsQL), which is used to assess the HRQoL of healthy or ill children, and the TAPQOL scale.

To improve the lives of individuals with DS, policies and strategies should be developed based on an assessment of their quality of life. A comprehensive understanding of children's quality of life (QoL) and its correlation with various factors that can either enhance or diminish it will aid policymakers and healthcare providers in designing interventions targeting modifiable factors that enhance QoL. Existing literature suggests that individuals with DS, both children and adults, exhibit lower levels of HRQOL.[8,9] Typically, children with trisomy 21 experience poor physical well-being. However, they demonstrate a high level of emotional well-being.[9] Several studies have established a relationship between sociodemographic characteristics and HRQOL in general populations worldwide.[10-12] However, additional data are required to examine the sociodemographic factors influencing HRQOL among under-five children with DS. The findings from previous studies are varied and inconclusive. Research has indicated that a higher level of family income is correlated with improved QoL outcomes. Likewise, advanced parental age, parental education, [13,14] and the stable relationship between the parent and child were associated with improved QoL. Finally, it was discovered that the child's gender had an influence on the domain of the school and learning environment. [6,15,16] Other studies did not find an association between socioeconomic status, [17] parental age, [18] or education. [15]

DS in Saudi Arabia is a critical public health concern that has received limited research attention. Consequently, additional data regarding the sociodemographic characteristics associated with HRQoL among this age group are required. Therefore, the objective of our study was to measure the HRQoL of under-five children with DS and to determine its correlation with specific sociodemographic characteristics among those children and their caregivers.

Subjects and Methods

Study design and population

This cross-sectional study enrolled preschool children with DS from Pediatric Departments across secondary care hospitals in the Western Region of Saudi Arabia, under the jurisdiction of the Ministry of Health. The sample size was calculated using EPI-INFO 2002 software. It was estimated that a minimum of 448 participants would be needed. This estimation was based on the assumption that 50% of preschoolers with DS might have a poor HRQoL, with a 5% precision, 90% confidence level, and a design effect of 2. The study used cluster sampling to ensure regional representativeness by selecting hospitals from Taif, Mecca, and Jeddah. The parents or caregivers of the children were contacted based on the information available in hospital records to request their participation.

Data collection and study instrument

Data collection was done using a structured interview questionnaire. The questionnaire encompassed sociodemographic data, such as parental age, education, occupation, marital status, consanguinity, living arrangements, attendance at counseling sessions, and medical history. Child-specific data collected included age, sex, nursery or preschool attendance, and primary caregiver.

Parental socioeconomic status (SES)

SES was assessed using four variables: parental educational level, family income, type of residence, and parental occupation. Scores ranged from 1 to 20, with categories indicating low SES (<5), low-middle SES (6–10), high-middle SES (11–15), and high SES (>15).^[19]

Health-related quality of life (HRQOL) assessment

The children's HRQOL was assessed using a translated Arabic version of the TNO-AZL TAPQOL scale, developed by the Netherlands Organization for Applied Scientific Research Academic Medical Center.^[20] The psychometric properties of the scale were assessed in different languages.^[21,22] The reliability of most TAPQOL scales was good, with Cronbach's alpha > 0.70.^[23] The instrument comprises 43 items distributed among 12 scales, encompassing physical, social, cognitive, and emotional domains. Responses were recorded using a scale that ranged from "never," "occasionally," to "often." The well-being of the child is assessed using a four-point scale for seven various domains, including ("stomach problems," "skin problems," "lung problems," "sleeping," "appetite," "motor functioning," and "communication"). If the participants indicate that these

issues occur "occasionally" or "often," the child's well-being is rated as either "fine," "not so good," "quite bad," or "bad." The scale scores were converted to a 0–100 scale, with higher scores indicating better HRQOL. [24]

Translation and validation procedures

The TAPQOL was translated into Arabic following established guidelines. The process involved initial translation by bilingual translators, followed by backward translation by native English speakers proficient in Arabic. Discrepancies in translations were addressed to ensure accuracy. The Arabic version's reliability was validated (Cronbach's $\alpha = 0.76$).

Statistical analysis

The data were analyzed using IBM SPSS Statistics Version 26. Categorical variables were summarized using frequencies and percentages, while continuous variables were described using means, ranges, standard deviations, medians, and interquartile ranges. Normality was assessed using the Shapiro–Wilk test. Statistical tests such as t-tests, ANOVA, Mann–Whitney, and Kruskal–Wallis tests were used. The level of statistical significance was set at P < 0.05. Multiple linear regression analysis was used to examine the correlation between HRQOL (dependent variable) and multiple independent variables.

Results

The demographic profile of the parents of children with Down's syndrome revealed a wide range of ages and educational backgrounds. Among the mothers, approximately half (218 (47.4%)) were between 36 and 45 years, while fathers were slightly older and 184 were (40.0%) between 46 and 55 years. Regarding educational attainment, 265 (57.6%) mothers and 211 (45.9%) fathers had university degrees. Regarding consanguinity, 38.9% of the parents have a history of consanguineous marriages. In terms of health, the majority of the parents (57.2%) reported no comorbidities. However, 99 (21.5%) and 66 (14.3%) had diabetes mellitus (DM) and hypertension, respectively [Table 1].

The study examined parents' educational backgrounds regarding DS and the characteristics of children and their caregivers. According to the findings, more than half (54.3%) of fathers and mothers were educated about DS by a doctor, while 45.7% did not receive any information [Figure 1].

The children in the current study varied in age, with 127 children (27.6%) aged 4–5 years representing the most popular age group. The gender distribution was equitable, with 221 (48.0%) male children. Attendance at nursery or kindergarten was nearly evenly divided, with 221 individuals (48.0%) in attendance. Regarding caregiving responsibilities, a majority (68.7%) of the children with DS were cared for by both parents [Table 2], which corresponds to 316 children [Table 2].

Table 1: Demographic characteristics of parents of children with Down's syndrome attending secondary care hospitals in Western Region, Saudi Arabia

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	Categories	Count	%
Mother's age	Less than 25	4	0.9%
	25-35	71	15.4%
	36-45	218	47.4%
	46-55	134	29.1%
	56-65	30	6.5%
	Older than 65	3	0.7%
Father's age	Less than 25	0	0.0%
	25-35	39	8.5%
	36-45	134	29.1%
	46-55	184	40.0%
	56-65	69	15.0%
	Older than 65	34	7.4%
Mother's	Illiterate	19	4.1%
educational level	Primary school graduate	5	1.1%
	Intermediate school graduate	47	10.2%
	High school graduate	111	24.1%
	University graduate	265	57.6%
	Postgraduate degree	13	2.8%
Father's	Illiterate	3	0.7%
educational level	Primary school graduate	20	4.3%
	Intermediate school graduate	49	10.7%
	High school graduate	128	27.8%
	University graduate	211	45.9%
	Postgraduate degree	49	10.7%
Mother's	Housewives	298	64.8%
occupation	Office clerk/administrative job	116	25.2%
	Service-oriented work	22	4.8%
	Trader or professional	9	2.0%
	Retired	15	3.3%
Father's	Unemployed	24	5.2%
occupation	Office clerk/administrative job	228	49.6%
	Service-oriented work	70	15.2%
	Trader or professional	23	5.0%
	Retired	115	25.0%
Marital status of	Together	433	94.1%
the family	Divorced	15	3.3%
•	Father is dead	12	2.6%
Consanguinity	Yes	179	38.9%
Comorbidities	None	263	57.2%
	Hypertension	66	14.3%
	Diabetic mellitus	99	21.5%
	Both hypertension and DM	27	5.9%
	Seizures	5	1.1%

The HRQOL for children with DS was assessed using the TAPQOL scale, yielding various scores across different domains. The sleeping mean score for physical functioning was 75.92, with a standard deviation of 18.38, ranging from 12.50 to 100. The average scores for appetite and skin health were higher (mean \pm SD = 83.53 \pm 22.17 and 85.68 \pm 16.86, respectively). The average score for lung health was 76.81, with a standard deviation of 25.78. Stomach issues had an average score of 80.60 \pm 23.60. Motor functioning had a high average score of 86.64 with a standard deviation of 19.62. The overall score was

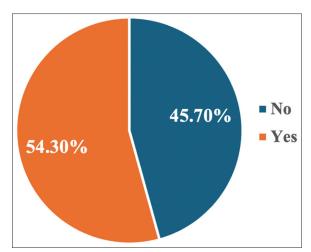


Figure 1: Percent of DS children's parents educated about DS by doctors

Table 2: Characteristics of preschool children with Down's syndrome attending secondary care hospitals in Western Region, Saudi Arabia

	Categories	Count	0/0
Child's age	<1 year	78	17.0%
	1-2 year	122	26.5%
	2-3 years	112	24.3%
	3-4 years	21	4.6%
	4-5 years	127	27.6%
Child's gender	Male	221	48.0%
	Female	239	52.0%
Does the child attend nursery/	No	239	52.0%
kindergarten?	Yes	221	48.0%
Responsible caregiver for a child with	Both parents	316	68.7%
Down syndrome?	Mothers	121	26.3%
	Sisters	23	5.0%
If the caregiver is someone other than	No	8	34.8%
the parents, Does he live with the child?	Yes	15	65.2%
If the answer is no, how many visits do you make to a caregiver for a child with Duane syndrome?	Daily	8	100.0%
If the caregiver is someone other than	No	4	17.4%
the parents, Was he educated about DS by the doctor?	Yes	19	82.6%

lower regarding social functioning, with a mean of 25.29 ± 30.24 and 64.98 ± 24.63 for social functioning and problem behavior, respectively. Regarding cognitive and emotional functioning, communication averaged 76.68 ± 17.81 , whereas anxiety had a mean score of 79.82 ± 23.81 . Positive mood and liveliness had notably low average scores of 19.51 ± 29.45 and 21.25 ± 29.16 , respectively. The mean overall TAPQOL score was 82.43, with a standard deviation of 12.00. The scores ranged from 43.00 to 100, indicating a generally good quality of life ($\geq 75\%$), with significant variability across different health domains [Figure 2].

The study examined the relationship between the HRQOL of children with DS and various demographic factors of their parents. The HRQOL scores showed no significant differences with regard

to the mother's or father's age (0.079 and 0.184, respectively). However, the education level of both mothers and fathers had a significant effect on HRQOL scores, with lower levels of education being associated with higher HRQOL scores (0.000 and 0.000, respectively). Furthermore, the occupations of both mothers and fathers were found to have a significant correlation with HRQOL. Specifically, unemployed mothers and fathers were associated with a lower HRQOL (0.002 and 0.000, respectively). In addition, it was found that parents with high and high-middle SES are associated with higher (83.79 and 84.3, respectively) mean scores of TAPQOL, with statistically significant differences (P = 0.000). Likewise, family marital status had a significant effect on HRQOL scores (P-value of 0.000). Parental consanguinity significantly impacted HRQOL scores (P-value of 0.002), with higher mean scores in nonrelated parents. The presence of comorbidities in parents significantly affected HRQOL scores (P-value of 0.000), whereas children whose parents had no comorbidities had a higher mean score. The doctor's education about Down syndrome did not significantly affect HRQOL scores [Table 3].

The study examined the correlation between the QoL of children with DS and various demographic factors pertaining to the children. The HRQOL scores showed significant variation in terms of the child's age, with lower mean scores in older children (P = 0.000). Factors such as gender, nursery or kindergarten attendance, the primary caregiver's identity, and cohabitation with the caregiver did not have a significant effect on HRQOL scores. In addition, there was no significant difference in HRQOL scores between caregivers who had received education about DS from a doctor. The children of educated caregivers scored an average of 86.57, while the children of noneducated caregivers scored an average of 77.00, with a P-value of 0.155 [Table 4].

The regression analysis [Table 5] was used to determine the relationship between the TAPQOL scores and sociodemographic characteristics among DS children under the age of five. The results revealed a positive correlation between the mother's age and the TAPQOL score (B = 2.845, Beta = 0.202, P = 0.007). In addition, the father's educational level has a strong positive and significant impact on the TAPQOL score (B = 4.071, Beta = 0.342, P < 0.001). Furthermore, the mother's profession significantly improved the TAPQOL score (B = 2.180, Beta = 0.168, P < 0.001). The marital status of the family had a significant positive effect on the TAPQOL score (B = 5.928, Beta = 0.178, P < 0.001). The quality of the relationship between parents had a significant negative effect on the TAPQOL score (B = -2.555, Beta = -0.104, P = 0.017). In addition, comorbidities were found to be negatively associated with the TAPQOL score (B = -3.222, Beta = -0.279, P < 0.001). No significant correlation was found between TAPQOL scores and any of the other factors [Table 5].

Discussion

In this study, we examined the HRQoL in children under the age of five with DS who attended the pediatric departments of

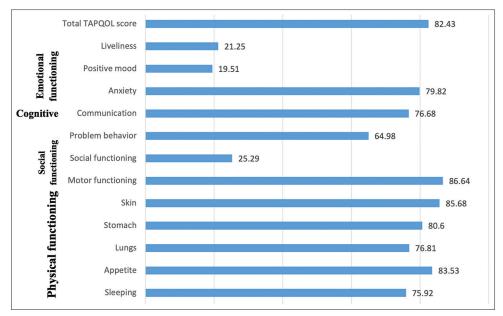


Figure 2: Health-related quality of preschool children with down syndrome according to the TAPQOL scale

secondary care hospitals at the Ministry of Health in the Western Region of Saudi Arabia. In addition, the study aimed to assess the sociodemographic characteristics of the children and their caregivers and examine the association between socioeconomic status and HRQoL. The findings provided valuable insights into the quality of life and sociodemographic factors affecting this population, revealing several significant trends and associations.

The HRQoL of children with DS was measured using the TAPQOL scale, encompassing various domains, including physical, social, and cognitive functioning. Overall, the TAPQOL scores indicated a high QoL, with an average score of 82.34. However, there was significant variation across different domains. This finding is consistent with several previous studies which demonstrated that children with DS exhibit moderate QoL levels. [18-27] Physical functioning scores were relatively high, with mean scores ranging from 75.92 for sleeping to 86.64 for motor functioning. These findings indicate that, regardless of their condition, a significant number of children with DS exhibit a relatively high level of physical health and functionality. [26,27] Nevertheless, certain domains, such as lung health and motor functioning, demonstrated more variability and room for improvement. The lower scores in lung health can be attributed to the common respiratory issues associated with DS, which require ongoing medical monitoring and intervention. [28,29]

Social functioning was more complex, exhibiting significant variability and generally lower scores than physical functioning. The mean score for overall social functioning was 25.29, suggesting significant difficulties in social interactions. This may indicate the social challenges and behavioral issues commonly observed in children with DS, which can affect their capacity to participate in regular social activities and interactions. The problem behavior scores exhibited a higher average of 64.98, indicating significant social difficulties as certain children

demonstrate superior coping abilities compared to their peers. The cognitive functioning scores for communication were relatively high, with a score of 76.68. However, the scores for positive mood and liveliness were notably low, with mean scores of 19.51 and 21.25, respectively. These findings align with previous studies indicating that children with DS often face significant cognitive and emotional challenges, impacting their overall well-being and QoL. [32,33]

An analysis of the sociodemographic factors of the parents yielded significant findings. The majority of mothers fell within the age range of 36 to 45 years, whereas fathers were typically aged between 46 and 55 years. Educational levels varied, with the majority of mothers holding a university degree and the majority of fathers having completed either high school or university. Interestingly, fathers' educational level showed a significant association with HRQoL scores. Children of illiterate fathers achieved the highest scores, while those whose fathers had completed primary school achieved the lowest scores. This finding contradicts the findings of Weijerman et al., [34] who illustrated that mothers belonging to the low-level education group demonstrated a lower HRQoL. This counterintuitive result might suggest that factors other than education, such as the father's involvement and support, play a crucial role in the child's QoL. [35] Furthermore, there was a significant correlation between the occupation of fathers and HRQoL, with children of unemployed fathers demonstrating the lowest scores. This finding highlights the significance of stable employment and economic support in enhancing the QoL in children with DS.[36] In addition, the assessment of the demographic factors of the children revealed no significant differences in HRQoL scores based on gender. The HRQoL scores of children under 1-year-old were the highest. However, this score decreased with age. This finding may suggest that the challenges associated with DS become more pronounced as children grow older and face

Table 3: The association between HRQOL of preschool children with Down syndrome and the demographic characteristics of their parents

Demographic characteristics			TAPQOL se	cale score
		Mean	SD	P
Mother's age	<5	89.00	0.00	F=1.99, P=0.079
	25-35	79.55	8.55	
	36-45	81.97	12.00	
	46-55	84.43	12.06	
	56-65	83.20	17.63	
	Older than 65	78.00	0.00	
Father's age	25-35	79.03	8.69	F=1.558, P=0.184
0	36-45	83.18	10.00	,
	46-55	82.34	12.47	
	56-65	84.17	13.86	
	Older than 65	80.29	15.14	
Mother's educational level	Illiterate	85.68	8.51	F=9.532, P=0.000*
	Primary school graduate	100.00	0.00	
	Intermediate school graduate	79.28	15.20	
	High school graduate	77.32	15.01	
	university graduate	84.52	8.65	
	Postgraduate degree	83.23	16.81	
Father's educational level	Illiterate	94.00	0.00	F=23.398, P=0.000*
ration of educational level	Primary school graduate	59.05	13.64	1 25.570,1 0.000
	Intermediate school graduate	79.22	13.83	
	High school graduate	82.44	9.59	
	university graduate	85.27	10.40	
	Postgraduate degree	82.16	10.67	
Mother's occupation	Unemployed	80.84	13.44	F=4.412, P=0.002*
Mother's occupation	Governmental employee	84.79	8.56	1-4.412, 1-0.002
	Private sectors employee	85.86	7.78	
	Own business	84.00	4.74	
	Retired	89.67	3.20	
Esther?		67.29	18.06	E-14.27 D-0.000*
Father's occupation	Unemployed	83.30		F=14.27, P=0.000*
	Governmental employee		10.65	
	Private sectors employee	83.56	12.91	
	Own business	75.52	7.51	
26 1 1	Retired	84.54	10.58	E 44.24 D 0.000#
Marital status of the family	Together	81.81	12.04	F=11.26, P=0.000*
	Divorced	95.33	3.52	
0	Father is dead	88.50	4.27	E 0.70 D 0.000
Consanguinity	No	83.80	10.95	F=9.70, P=0.002*
	Yes	80.26	13.24	
Comorbidities	None	83.47	10.54	F=12.85, P=0.000*
	Hypertension	87.59	8.72	
	Diabetic mellitus	79.00	14.78	
	Both hypertension and DM	76.37	12.36	
	Seizures	60.00	0.00	
Father and mother were educated	No	82.27	11.38	F=0.064, P=0.800
about Down Syndrome by the doctor	Yes	82.56	12.52	
Sociodemographic level	Low SES	86.75	9.56	F=11.77, P=0.000*
	Low-middle SES	75.48	16.06	
	High-middle SES	83.79	10.21	
	High SES	84.30	13.14	

^{*}Significant association was assessed using independent samples t-test, ANOVA, Mann-Whitney, and Kruskal-Wallis tests

more complex social and cognitive demands. This aligns with the findings of Lee *et al.*,^[16] which demonstrated that age influences emotional and material well-being, interpersonal relations, and social inclusion. Gender had no significant effect on HRQoL,

suggesting that both boys and girls with DS have comparable levels of QoL. These findings align with previous research, such as the study conducted by Lee *et al.*,^[16] who reported that the quality of life did not significantly differ between genders.

Table 4: Association between HRQOL and characteristics of preschool children with Down syndrome

Children characteristics			TAPQOL scale score	
		Mean	Standard Deviation	P
Child's age	<1 year	87.47	10.35	F=7.330
	1-2 year	80.74	11.63	P=0.000*
	2-3 years	79.31	13.23	
	3-4 years	79.43	11.14	
	4-5 years	84.19	11.13	
Child's gender	Male	81.97	13.40	F=618
	Female	82.85	10.56	P=0.432
Does the child attend nursery/kindergarten?	No	82.03	11.65	F=0.555
	Yes	82.86	12.38	P=0.457
Responsible caregiver for a child with Down syndrome?	Both parents	81.76	11.47	F=1.675
	Mothers	83.70	13.22	P=1.89
	Sisters	84.91	12.11	
If the caregiver is someone other than the parents, does	No	88.50	12.29	F=1.08
he live with the child?	Yes	83.00	11.98	P=0.310
If the caregiver is someone other than the parents, was	No	77.00	0.00	F=2.179,
he educated about Down Syndrome by the doctor?	Yes	86.58	12.74	P=0.155

^{*}Significant association was assessed using independent samples t-test, ANOVA, Mann-Whitney, and Kruskal-Wallis tests

Table 5: Regression analysis of TAPQOL score and sociodemographic characteristics among children under-five with Down Syndrome

Model	Un-standardized Coefficients		Standardized Coefficients	t	Sig.
	В	Std. Error	Beta		
Mother's age	2.845	1.056	0.202	2.693	0.007
Father's age	-1.243	1.006	-0.106	-1.236	0.217
Mother's educational level	-0.833	0.638	-0.071	-1.305	0.193
Father's educational level	4.071	0.572	0.342	7.112	0.000
Mother's occupation	2.180	0.605	0.168	3.602	0.000
Father's occupation	0.807	0.470	0.089	1.718	0.087
Marital status of the family	5.928	1.511	0.178	3.922	0.000
Socioeconomic score	-0.108	0.161	-0.424	-1.46	0.502
Relation between parents	-2.555	1.071	-0.104	-2.385	0.017
Comorbidities	-3.222	0.512	-0.279	-6.291	0.000
Father and mother education about DS by the doctor?	1.307	1.069	0.054	1.223	0.222
Child's age	0.350	0.382	0.042	0.917	0.360
Child's gender	-0.887	1.074	-0.037	-0.826	0.409
Does the child attend nursery/kindergarten?	-1.434	1.060	-0.060	-1.353	0.177
Responsible caregiver for a child with Down syndrome?	0.330	0.965	0.016	0.342	0.732

a. Dependent Variable: DS Preschool children Quality of Life

The study also examined the impact of educational interventions conducted by healthcare professionals. Parents who received education about DS from a doctor had slightly higher scores for the HRQoL of their children. However, this difference did not reach statistical significance. This highlights the potential value of educational support and resources for parents in managing DS, even if the immediate impact on HRQoL needs to be pronounced. Educating parents can equip them with better coping strategies and knowledge to effectively meet their children's needs.^[15,37]

Overall, the findings highlight the complex interplay between physical, social, and cognitive factors in determining the HRQoL of children with DS. Parents' sociodemographic characteristics, particularly fathers' education and occupation, were found to be critical factors affecting HRQoL. The study suggests that interventions targeting the enhancement of economic and educational assistance for families could have a beneficial effect on the QoL of children with DS.

Limitation and future aspects of the study

There is a scarcity of studies on HRQoL among DS preschool children in Saudi Arabia. In addition, studies examining the association between HRQoL and sociodemographic characteristics among this age group require further improvement. However, the main limitation of this research was related to the self-evaluation of the questionnaire. Although self-evaluated questionnaires are commonly used in various research studies, they may be subject to bias due to the possibility that respondents may not have provided an objective evaluation. Another

limitation is that this study used a cross-sectional design. Longitudinal studies are recommended to examine the causal effect of sociodemographic variables on the QoL of children with DS.

Conclusion

In conclusion, this study provides a detailed assessment of the HRQoL of children with DS in the Western Region of Saudi Arabia. The findings highlight the significance of sociodemographic factors in shaping their well-being. Overall, the TAPQOL scores indicated a high QoL, with an average score of 82.34, though there was considerable variability across different domains. Furthermore, when evaluating the demographic characteristics of the children, it was found that the scores for HRQoL did not show any significant variation based on the child's age or gender. The sociodemographic characteristics of parents, particularly the education, occupation, and SES of fathers, were found to be important factors influencing the HROoL. The findings support the implementation of comprehensive support strategies that address the medical, economic, and educational aspects to enhance the QoL of children with DS and their families. Furthermore, it is crucial to implement specific interventions that aim to enhance the social and emotional abilities of children with Down syndrome to successfully address the areas in which they encounter the most substantial difficulties. Further research is needed to investigate the long-term impacts of these factors and to develop targeted interventions that can effectively address the unique needs of this population.

Acknowledgments

We thank residents, colleagues, and administrative staff at the Taif Program of Preventive Medicine, Public Health Administration, Makkah Health Affairs, Ministry of Health, Saudi Arabia.

Institutional review board (IRB) approval and patients' consent

This study was conducted according to the guidelines laid down in the Declaration of Helsinki, and all procedures involving research study participants were approved by The Research Ethics Committee of Makkah Health Affairs, Ministry of Health, Saudi Arabia (IRB. H-02-K-076-0324-1097) approved all research procedures, and written informed consent was obtained from all study participants.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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