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Factors influencing quality of life in children with tracheostomy with emphasis on home care visits: a multi-centre investigation

B Mirza[1], A Marouf[2,*], F Abi Sheffah[2], O Marghlani[2,3], J Heaphy[2], A Alherabi[2,3], F Zawawi[1], I Alnoury[1] and T Al-Khatib[1,2]

[1]Department of Otolaryngology – Head and Neck Surgery, Faculty of Medicine, King Abdulaziz University, Jeddah, [2]Department of Surgery, Otolaryngology – Head and Neck Surgery Section, King Faisal Specialist Hospital and Research Centre, Jeddah and [3]Department of Otolaryngology – Head and Neck Surgery, College of Medicine, Umm Al-Qura University, Makkah, Saudi Arabia

Main Article

*Co-first author

Dr A Marouf takes responsibility for the integrity of the content of the paper

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Author for correspondence:
Dr A Marouf,
Department of Surgery, Otolaryngology – Head and Neck Surgery Section,
King Faisal Specialist Hospital and Research Centre, Prince Saud Al Faisal Street,
Jeddah 11211, Saudi Arabia
E-mail: axm1676@case.edu

Abstract

Objective. Only a few studies have assessed the quality of life in children with tracheostomies. This study aimed to evaluate the quality of life and the factors influencing it in these children.
Method. This cross-sectional, two-centre study was conducted on paediatric patients living in the community with a tracheostomy by using the Pediatric Quality of Life Inventory. Clinical and demographic information of patients, as well as parents' socioeconomic factors, were obtained.
Results. A total of 53 patients met our inclusion criteria, and their parents agreed to participate. The mean age of patients was 6.85 years, and 21 patients were ventilator-dependent. The total paediatric health-related quality of life score was 59.28, and the family impact score was 68.49. In non-ventilator-dependent patients, multivariate analyses indicated that social functioning and health-related quality of life were negatively affected by the duration of tracheostomy. The Quality of Life of ventilator-dependent patients was influenced by care visits and the presence of pulmonary co-morbidities.
Conclusion. Children with tracheostomies have a lower quality of life than healthy children do. Routine care visits by a respiratory therapist and nurses yielded significantly improved quality of life in ventilator-dependent children.

Introduction

A tracheostomy is a temporary or permanent opening in the cervical trachea with a breathing tube positioned in front of the neck.[1] The number of paediatric tracheostomies is increasing in the USA and in some countries in Europe.[2,3] Although the reported increase in number in the USA is small and insignificant, the length of stay and costs of care associated with it have increased significantly from 2010 to 2018.[2] Tracheostomising a child as a result of infection has been notably less frequent in recent decades than it was previously because of the introduction of vaccines.[4,5] Today, more common indications for tracheostomy include airway stenosis, prematurity and neuromuscular disorders.[1,4-6]

Complication rates and mortality rates associated with tracheostomies are high, especially in children.[1,4,5] However, mortalities in most cases are not a result of tracheostomy or tracheostomy complications per se but rather are a result of the underlying conditions. Less than 6 per cent of deaths in this population are attributed directly to tracheostomy.[1,5] These indications, complications and mortality rates are similar to those reported in Saudi Arabia.[7,8]

Several quality-of-life (QoL) domains in a child with tracheostomy are altered. Given the influence tracheostomy has on voice and speech, and the resultant social isolation, children with tracheostomy face a significant reduction in their general well-being.[9,10] These children have been found to have impaired QoL more than other patients with serious chronic illnesses do, including those with end-stage renal disease and malignancy.[11,12] There appears to be a paucity of QoL data for paediatric patients with tracheostomy in general and in the Middle East specifically. A few qualitative and quantitative studies have, however, assessed the QoL of these patients.[9,10,12–14]

Parental training to care for a tracheostomy requires organised training plans and preparation because parents may initially be overwhelmed with concerns about their ability to care for their children.[13,15–17] In Saudi Arabia, depending on the level of training and experience, even nurses might not be confident about caring for a patient with a tracheostomy.[18] Parents' perceptions of having a child with a tracheostomy and its effects have been well studied, but limited data exist on this topic from the Middle East and North Africa. The literature has constantly shown that there are difficulties in recruiting home nurses and that there is a shortage in the provision of home nursing care compared with patients' needs.[9,46] In general, parents with a child with tracheostomy experience a significant burden and have moderate distress.[10,20,21] Four aspects of the burden can be

considered: social, emotional well-being, daily living and physical functioning.[15,22] These aspects are measured by the Pediatric Quality of Life Inventory Family Impact Module, a validated QoL instrument that assesses the impact of chronic illnesses on the family's QoL.[23]

Using the Pediatric Quality of Life Inventory, we aimed to assess the QoL and the factors influencing it in children with tracheostomies and their parents. We aimed to investigate how routine home care visits influence the QoL in ventilator-dependent children. Although many studies alluded to the concept of home visits for children with tracheostomy and the benefits associated with it,[24–26] this is the first study to assess its impact on QoL using comparative and quantitative data.

Materials and methods

Participants

This multicentre, cross-sectional, observational study was conducted at two tertiary care centres. Paediatric patients with a tracheostomy and aged less than 18 years who were living in the community and who had undergone a tracheostomy tube insertion between 2010 and 2020 were included.

Patients diagnosed with psychiatric conditions or paralysis (hemiplegia, diplegia, paraplegia and quadriplegia) and patients who were completely bed-bound because of mechanical ventilation were excluded because assessing physical, cognitive and social functioning in these patients is difficult using standard questionnaires. In addition, patients who were tracheostomised and kept in the intensive care unit, and non-Arabic-speaking families were excluded. Ethical approval was obtained from the Office of Research Affairs (reference number: 2021-16) and the Unit of Biomedical Ethics (registration number: HA-02-J-008, reference number: 29/21).

Before starting the questionnaire, participants were informed about the purpose of the study and the approximate duration of the questionnaire, and those who agreed to participate were registered.

Parents answered questions on the child's characteristics and family information, including patient age, gender, chronic diseases, number of siblings, monthly income, parents' education level and residence area. Furthermore, we recorded information on the tracheostomy tube, such as tracheostomy operation date, ventilatory status, co-morbidities, duration of tracheostomy and routine home visits.

Routine home care visits

Ventilator-dependent patients were candidates for routine home visits every 3–4 days. The home visit team consists of trained nurses and a respiratory therapist and provides patients with routine tracheostomy care, such as suctioning, changing tubes and adjusting ventilator settings, as needed. In addition, the team further coordinates with the family from an early stage to provide help and instructions regarding acute problems. They also continuously assess the need for emergency care and emotional support. This service is provided freely by the government and does not require parents to pay any fees for receiving it.

Questionnaire

Pediatric Quality of Life Inventory Generic Core

In this study, the scores from the Pediatric Quality of Life Inventory 4.0 Generic Core Scales were used. Pediatric Quality of Life Inventory questionnaires have a pre-established validity for children with chronic diseases, including respiratory diseases.[11,14,27] Arabic versions of the questionnaires had already been validated in both healthy and ill children.[28–31] The scores for the Pediatric Quality of Life Inventory Generic Core include two sets of questionnaires: physical and psychosocial functioning. The two scores are merged to give the total paediatric health-related QoL score.

Family Impact Module

The Family Impact Module contains two sets of questionnaires: parent health-related QoL and family functioning. It has also been validated in Arabic.[28,32]

Scoring

Parents responded to each questionnaire item on a five-point Likert scale that ranged from 0 (never a problem) to 4 (almost always a problem). The score was reverse linearly transformed from 0 (worst functioning) to 100 (best functioning) in accordance with Pediatric Quality of Life Inventory scoring guidelines. Higher values equalled better QoL. The various Pediatric Quality of Life Inventory Generic Core scores were compared with normative data of children reported by Abdul-Rasoul *et al*.[31] These normative data are from healthy children of various ages in Kuwait (a Gulf country that is demographically, geographically and culturally similar to Saudi Arabia). The total family impact score, as well as the parent QoL and family functioning summary scores, were calculated by using the Family Impact Module questionnaire.

Statistical analysis

Data were analysed with SPSS® statistical analysis software. The Shapiro–Wilk test was used to evaluate the normality of data distribution. Because inherent differences in the overall well-being and illness severity exist between patients who are ventilator-dependent and patients who are not, it was decided to separately analyse their data. Normally distributed parametric data were compared by using a one-way analysis of variance or independent samples *t*-test, and non-normally distributed data were compared by using the Kruskal–Wallis or Mann–Whitney U test. Pearson correlation was used to find an association between measure parameters. Multivariate linear regression analyses were employed to assess the impact of different covariates on QoL. A p-value of less than 0.05 was considered statistically significant.

Results

Clinical and demographic characteristics

During the study period, 122 children underwent surgical tracheostomy procedures at the two centres. From this group, 61 children (families) received the questionnaire, of which 53 were recruited for the study. The response rate was 86.9 per cent. Patients from centre A represented 60.4 per cent of the sample, and those from centre B represented 39.6 per cent of the sample. There were no significant differences between the two centres in any aspect. All participants followed up with the otolaryngology head and neck surgery clinics every eight weeks. (Figure 1).

The children's clinical and demographic characteristics are presented in Table 1. There were more male than female

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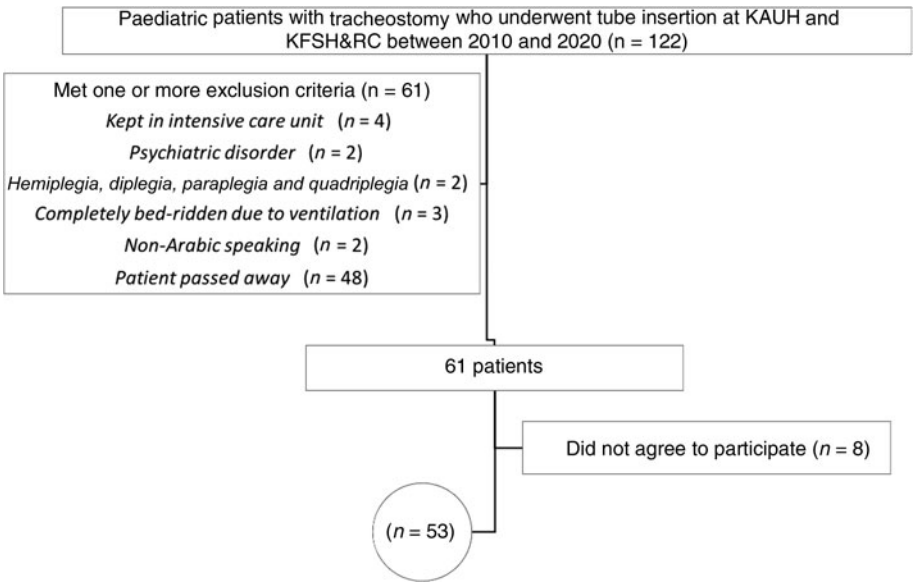

Fig. 1. Flow diagram of the selection process. KAUH = King Abdulaziz University Hospital (Jeddah, Saudi Arabia); KFSH&RC = King Faisal Specialist Hospital and Research Centre (Jeddah, Saudi Arabia).

children (60.4 per cent *vs* 39.6 per cent, respectively). Their mean age was 6.85 ± 4.19 years. The reported durations of tracheostomy were as follows: less than 1 year, 17.0 per cent; 1 to less than 2 years, 17.0 per cent; and 2 to 4 years, 35.8 per cent. The mean duration of tracheostomy was 3.64 ± 3.37 years. The most frequent co-morbidities were airway diseases (56.6 per cent), and 39.6 per cent of the patients were ventilator-dependent.

Summary scores

The total health-related QoL score of patients with tracheostomies, as assessed from the answers reported by their parents, was 59.28. All Pediatric Quality of Life Inventory Generic Core Scale scores were significantly lower than the normative scores of healthy children reported by Abdul-Rasoul *et al.*[31] ($p < 0.001$), except for physical symptoms and cognitive functioning scores because normative data were not available for these two subscales (Figure 2a)

The parent health-related QoL summary scores consisted of six scores, the highest mean being the cognitive functioning score (74.72), followed by the communication score (69.34). The mean parent health-related QoL summary score was 65.94. Family functioning health-related QoL consisted of two scores: the family relationships score (87.17) and the daily activities score (55.66). The mean family functioning health-related QoL was 75.35, and the mean family impact total score was 68.49. Figure 2b represents a further breakdown of the Pediatric Quality of Life Inventory Family Impact Module scales.

Factors influencing the quality of life

Age

The ages of the patients did not appear to significantly influence any of the Generic Pediatric Quality of Life Inventory scores or Family Impact Module subscales ($p > 0.05$).

Gender and socioeconomic status

In both patients who were ventilator-dependent and patients who were not, insignificant differences were observed in all QoL subscales in relation to gender and socioeconomic status (educational level, income, number of children and residence; data not shown).

Duration of tracheostomy

In patients who were not ventilator-dependent, significant differences were noted in both children's social functioning score and the total paediatric health-related QoL and the duration of tracheostomy, with the highest score being for a duration of less than 1 year and the lowest for a duration of 2 to less than 4 years ($p = 0.008$, $p = 0.013$, respectively). A significant negative correlation between children's social functioning score and the duration of tracheostomy was found ($r = -0.450$). These results were confirmed after adjusting for different co-morbidities in multivariate linear regression ($p < 0.05$). Furthermore, patients who were not ventilator-dependent and had been cannulated for less than 1 year had a better cognitive functioning score than patients with 1 to less than 2 years of cannulation ($p = 0.002$). Comparison in other duration groups was not possible because no patients completed the cognitive functioning subscale in these groups. In ventilator-dependent children, the duration of tracheostomy did not appear to influence the total paediatric health-related QoL or any of the subscales, or the Family Impact Module subscales (Tables 2 and 3).

Co-morbidities

For children who were not ventilator-dependent, the presence of an airway disease significantly affected emotional functioning score (71.58 *vs* 50.72, $p = 0.024$) in univariate analysis. However, this association was not significant in multivariate regression ($p = 0.077$).

For ventilator-dependent children, pulmonary diseases significantly influenced physical function (51.33 *vs* 13.92; $p = 0.007$), social functioning (65.66 *vs* 46.67; $p = 0.023$) and total health-related QoL scores (59.73 *vs* 39.55; $p = 0.003$). Multivariate analyses adjusting for the duration of tracheostomy and other co-morbidities confirmed these findings ($p < 0.05$). Airway and genetic diseases seemed to significantly influence some QoL subscales, but multivariate analyses failed to confirm these findings, indicating potential confoundment.

Home care visits

There were 21 (39.6 per cent) patients who were ventilator-dependent, of whom 14 received routine care visits. Patients who did not receive home visits (33.3 per cent) opted out of this service or resided far away from their corresponding centre. They did not necessarily reside in rural areas or have low

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Table 1. Clinical and demographic characteristics of studied patients (n= 53)*

Parameter	Value
Age (mean ± SD; years)	6.85 ± 4.19
Duration of time with tracheostomy (mean ± SD; years)	3.64 ± 3.37
Co-morbidities (n (%))	
– Pulmonary disease	5 (9.4)
– Neurological disease	15 (28.3)
– Cardiovascular disease	11 (20.8)
– Endocrine disease	6 (11.3)
– Airway disease	30 (56.6)
– Genetic syndrome	7 (13.2)
Main indication for tracheostomy (n (%))	
– Respiratory failure	18 (34)
– Airway obstruction	31 (58.5)
– Recurrent seizures	2 (3.8)
– Other	2 (3.8)
On home ventilation (n (%))	
– No	32 (60.4)
– Yes	21 (39.6)
– Routine home visits	14 (66.7)
– No routine home visits	7 (33.3)
Parents' educational level (n (%))	
– Primary school	3 (9.5)
– Intermediate school	7 (13.2)
– High school	17 (32.1)
– University and above	24 (45.3)
Family monthly income (n (%))	
– <5000 SR (≈1333 USD)	17 (32.1)
– 5000–10000 SR (≈1333–2666 USD)	20 (37.2)
– 10 000–20000 SR (≈2666–5333 USD)	11 (20.8)
– >20 000 SR (≈5333 USD)	5 (9.4)
Number of children at home (n (%))	
– 1	5 (9.4)
– >1	48 (90.6)
Residence (n (%))	
– Jeddah	32 (60.4)
– Outside Jeddah, non-rural	12 (22.6)
– Outside Jeddah, rural	9 (17)

* SR = Saudi Riyal; USD = US dollar

socioeconomic status. Only one patient of those who did not receive home visits lived outside Jeddah in a rural area (data not shown). The remaining six patients who did not receive home visits either opted out or lived in a non-rural city far away from Jeddah. Many patients resided outside Jeddah but still received visits because their residence city was close to Jeddah. Regardless of residence area type and distance from the hospital, ventilator-dependent patients were appropriately transported from their homes to the hospital for regular follow-up appointments and, if needed, were provided with special transport services.

The results of this study indicate that patients who received routine home care visits had significantly better social functioning scores (72.41 *vs* 40.43, $p = 0.010$) and total health-related QoL scores (64.37 *vs* 41.81, $p = 0.021$) than patients who did not receive them. After controlling for the duration of tracheostomy, residence and co-morbidities, the results remained significant in multivariate analyses ($p < 0.05$) (Tables 1, 2 and 3).

Discussion

In this work, we set out to investigate the QoL of children with tracheostomies and their families in two tertiary centres. Our study had a response rate of 86.9 per cent, representing 53 families. To our knowledge, this is the first study to assess QoL among paediatric patients with tracheostomies in the Middle East and North Africa.

Results showed that the total health-related QoL score was 59.28. Higher scores were found for individual symptoms and emotional and psychosocial functioning than for physical functioning. A similar pattern was noted in a study by Westwood *et al.*[10] The average health-related QoL scores in healthy children reported by Varni *et al.*[11] and Abdul-Rasoul *et al.*,[31] however, were 83.84 and 88.2, respectively. Several important observations can be noted from our results. It appears that the age of the child did not significantly impact any of the Generic Core subscales. However, a longer duration of tracheostomy was found to negatively affect the social and emotional functioning of children with tracheostomies who were not ventilator dependent. This is an interesting finding, as it has been shown that a longer duration of tracheostomy negatively affects children's speech and language outcomes,[33,34] which might account for the negative impact of tracheostomy duration on social functioning. The duration of tracheostomy in ventilator-dependent children did not influence any of the QoL scales. The ventilatory status in these patients possibly further impeded their ability to communicate and physically function and made the effects of tracheostomy duration on QoL trivial.

In ventilator-dependent children, pulmonary co-morbidities appeared to negatively impact physical and social functioning, and the total paediatric health-related QoL. Although previous reports indicated that a pulmonary diagnosis is associated with a longer duration of mechanical ventilation and higher mortality in children with tracheostomies,[6,35–37] the duration of tracheostomy cannot explain the worse QoL associated with pulmonary diseases in ventilator-dependent patients seen in this study because the findings in this study were confirmed by regression analyses. Furthermore, these reports were based on hospitalised patients in the intensive care unit, not patients living in the community. We hypothesise that the ventilatory dependence status is responsible for these significant results in the ventilator-dependent group.

From the results of this study and previous publications,[33,34] earlier decannulation, when possible and clinically safe, could be associated with better speech and language outcomes and could improve patient communication and social QoL. Having friends was also noted to be important for communication in children with a tracheostomy.[13] The difficulties imposed by tracheostomy on physical functioning and activity should not be overlooked, in particular that physical functioning scores represented the worst aspect of QoL relative to other scores. Methods should be developed to facilitate physical functioning in this fragile population. Children with

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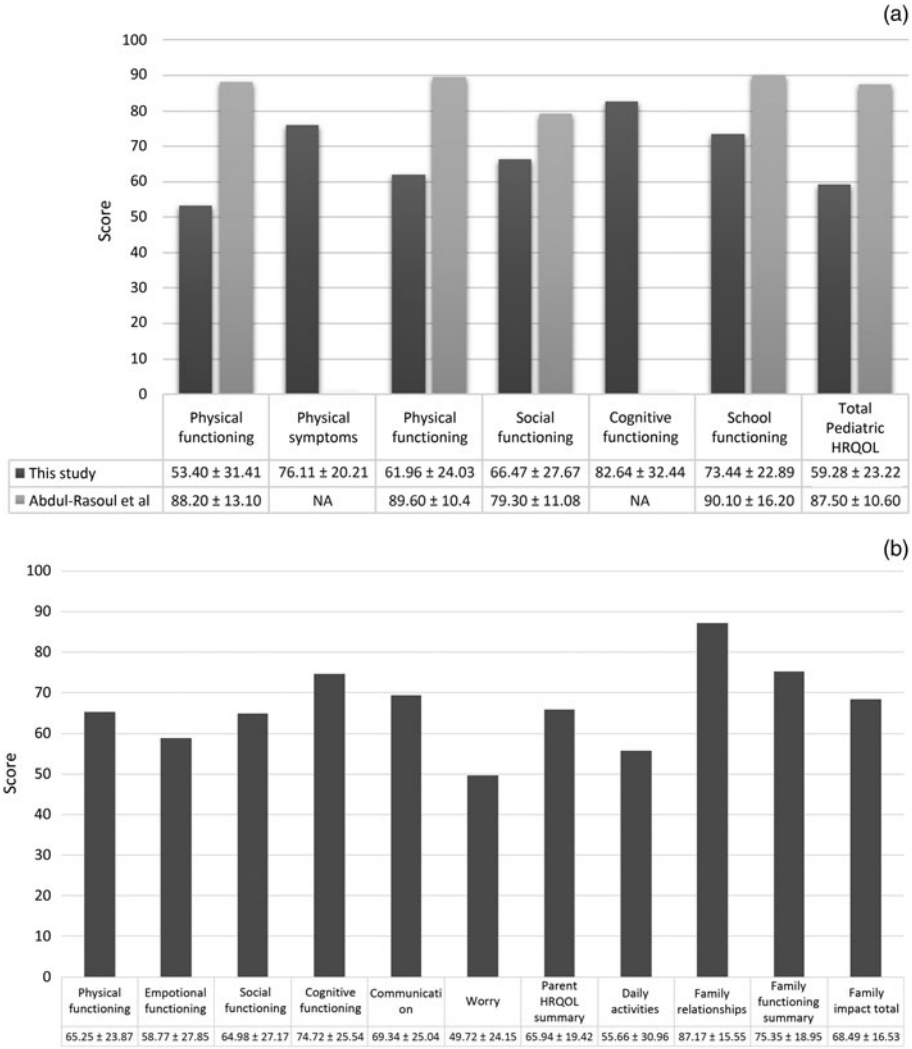

Fig. 2. (a) Mean of Family-Reported Pediatric Quality of Life Inventory Generic Core Scales and Pediatric Quality of Life Inventory Infant Scales of Studied Patients ($n = 53$) and their normal counterparts from Abdul-Rasoul *et al.*[31] (b) Scale descriptive of the Pediatric Quality of Life Inventory Family Impact Module scores of studied patients ($n = 53$). Higher values equal better health-related quality of life. Data are expressed as mean ± standard deviation. HRQoL = health-related quality of life; NA = not available

tracheostomy are encouraged to perform physical activity as are healthy children, to the extent they can tolerate. However, water and contact sports should be avoided.[38]

The benefits of involving a speech and language pathologist, as a part of a multidisciplinary team, in the care of children with tracheostomies have been previously described.[24,33,38,39] Despite this, not all children with tracheostomy visit and get assessed by speech and language pathologists and are often not referred to one or only referred when their communication impairment is profound.[40,41] This occurs partially because physicians have many unanswered questions when they care for children with tracheostomies.[42] Unfortunately, a guideline for the care of tracheostomy in children is lacking, especially when it comes to speech and language pathologist referral.[42–44] In light of this, based on the findings of this study and previous publications,[38,40,42–47] we recommend that patients who have a tracheostomy for more than two years or show moderate speech impairment be seen and evaluated by a speech and language pathologist if decannulation is not suitable.

The American Academy of Otolaryngology–Head and Neck Surgery convened a panel to recommend a consensus statement for paediatric tracheostomy care based on a review of the literature. The majority of the findings from the literature were not controlled and consisted mainly of books and experts' opinions.[43] The panel recommended considering home nursing care if the caregivers are unable to adequately care for the patient. They also indicated the need for further research on defining quality care in these children and further research on factors affecting their outcomes. Based on the findings of our study, we recommend providing children with tracheostomy who are ventilator-dependent with home care visits. Routine visits to these patients every 3–4 days significantly improved their social functioning and total health-related QoL, independent of their co-morbidities and residence location. Children who received the visits had 79.1 per cent better social functioning and 54 per cent better total health-related QoL. Edwards *et al.* have previously indicated that home nursing care is necessary for children with tracheostomy and ventilatory dependence. They also indicated that the amount of help should be tailored for each patient based on his or her condition and the degree of ventilatory dependence.[19] Caregivers have sounded their need for home nursing in previous publications.[19,48] The present study is the first to demonstrate QoL improvements using a control group and quantitative data.

The total family impact score in our study was 68.49. The parent health-related QoL score was 65.94, with the lowest parent health-related QoL scores being social, emotional and caregiver worry (64.98, 58.77 and 49.72, respectively). To a great extent, these findings echo much of the literature, as these scores have ranked among the lowest within parent health-related QoL.[10,22,49] The issue of social isolation has been previously reported in many publications.[10,15,50] Emotional support has been identified as an important aspect

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Table 2. Factors associated with the Pediatric Quality of Life Inventory in children with tracheostomy

Parameter	Physical functioning		Physical symptoms		Emotional functioning		Social functioning		Cognitive functioning		Total paediatric HRQoL	
Not ventilator-dependent (n = 32)	32		7		32		32		7		32	
Age	r = 0.007	p = 0.972	r = –0.116	p = 0.805	r = –0.176	p = 0.336	r = –0.128	p = 0.485	r = –0.401	p = 0.373	r = –0.018	p = 0.923
Duration of time with tracheostomy												
– <1 year	70.05 ± 22.80		87.00 ± 2.74	p = 0.203	76.52 ± 17.74		93.75 ± 14.08		100.0 ± 00.0	p = 0.002†	77.57 ± 14.32	
– 1 to <2 years	71.70 ± 22.60	p = 0.077	75.00 ± 21.21		56.32 ± 29.70	p = 0.203	70.42 ± 20.76	p = 0.008†	81.25 ± 8.84		65.43 ± 11.14	p = 0.013†
– 2 to <4 years	32.81 ± 33.95				50.50 ± 26.08		52.00 ± 30.39				43.30 ± 28.23	
– ≥ 4 years	66.41 ± 21.17				57.50 ± 28.28		63.44 ± 26.82				64.62 ± 20.34	
Correlation co-efficient	r = –0.183	p = 0.317	r = –0.097	p = 0.836	r = –0.281	p = 0.119	r = –0.450	p = 0.010†	r = –0.809	p = 0.028†	r = –0.275	p = 0.128
Co-morbidities												
– Pulmonary (no *vs* yes)	56.98 *vs* 70.31 (p = 0.847)		83.33 *vs* 85.0 (p = 0.900)		58.89 *vs* 74.17 (p = 0.437)		68.00 *vs* 80.0 (p = 0.581)		93.75 *vs* 100 (p = 0.604)		60.43 *vs* 75.00 (p = 0.413)	
– Neurologic (no *vs* yes)	62.86 *vs* 35.94 (p = 0.050)		–		59.62 *vs* 60.83 (p = 0.921)		72.50 *vs* 52.50 (p = 0.087)		–		64.16 *vs* 49.16 (p = 0.170)	
– CVS (no *vs* yes)	54.86 *vs* 73.75 (p = 0.220)		83.00 *vs* 85.00 (p = 846)		56.71 *vs* 76.76 (p = 0.120)		66.11 *vs* 83.0 (p = 0.220)		92.50 *vs* 100.0 (p = 0.41)		58.56 *vs* 76.37 (p = 0.128)	
– Endocrine (no *vs* yes)	56.44 *vs* 67.45 (p = 0.602)		82.00 *vs* 87.50 (p = 0.58)		60.52 *vs* 55.10 (p = 0.707)		69.38 *vs* 64.38 (p = 1.00)		97.50 *vs* 87.50 (p = 0.26)		61.15 *vs* 62.69 (p = 0.906)	
– Airway (no *vs* yes)	54.91 *vs* 60.7 (p = 0.667)		86. 25 *vs* 80.00 (p = 0.59)		71.58 *vs* 50.72 (p = 0.024)†		70.0 *vs* 67.78 (p = 0.561)		100.0 *vs* 87.50 (p = 0.09)		64.09 *vs* 59.21 (p = 0.575)	
– Genetic (no *vs* yes)	61.90 *vs* 29.17 (p = 0.054)		82.50 *vs* 90.00 (p = 0.56)		59.58 *vs* 61.67 (p = 0.885)		70.36 *vs* 57.50 (p = 0.424)		93.75 *vs* 100.0 (p = 0.60)		63.70 *vs* 44.84 (p = 0.142)	
Ventilator-dependent(n = 21)	21		2		21		21		2		21	
Age	r = 0.070	p = 0.760	–	–	r = –0.343	p = 0.128	r = 0.183	p = 0.439	–	–	r = 0.078	p = 0.738
Home visits												
– Yes	53.73 ± 31.76		70.0 ± 0.00		66.43 ± 22.57		72.41 ± 23.51				64.37 ± 19.49	
– No	30.51 ± 30.71	p = 0.127	30.0 ± 0.00	–	62.66 ± 15.48	p = 0.697	40.43 ± 21.00	p = 0.010†	–	–	41.81 ± 18.93	p = 0.021†
Duration of time with tracheostomy												
– <1 year	41.67 ± 0.00		30.0 ± 0.00		63.64 ± 0.00		12.50 ± 0.00				37.14 ± 0.00	
– 1 to <2 years	43.06 ± 38.72		70.0 ± 0.00	–	81.67 ± 7.64		77.92 ± 32.99		–	–	64.91 ± 25.75	
– 2 to <4 years	55.68 ± 30.05	p = 0.718	–		66.11 ± 23.56	p = 0.415	66.11 ± 21.18	p = 0.195			64.42 ± 19.00	p = 0.309
– ≥ 4 years	36.72 ± 36.82		–		58.13 ± 18.31		59.29 ± 27.45				47.78 ± 22.32	
Correlation co-efficient	r = –0.040	p = 0.864	–	–	r = –0.406	p = 0.086	r = –0.062	p = 0.795	–	–	r = –0.182	p = 0.430
Co-morbidities												
– Pulmonary (no *vs* yes)	51.33 *vs* 13.92 (p = 0.007)†		–		65.48 *vs* 63.33 (p = 0.931)		65.66 *vs* 46.67 (p = 0.023)†		–		59.73 *vs* 39.55 (p = 0.003)†	
– Neurologic (no *vs* yes)	51.56 *vs* 34.83 (p = 0.279)		–		68.57 *vs* 58.38 (p = 0.286)		69.23 *vs* 50.89 (p = 0.150)		–		61.60 *vs* 47.36 (p = 0.163)	
– CVS (no *vs* yes)	44.43 *vs* 52.60 (p = 0.664)		–		61.98 *vs* 78.75 (p = 0.138)		59.53 *vs* 75.94 (p = 0.286)		–		54.43 *vs* 67.14 (p = 0.305)	
– Endocrine (no *vs* yes)	46.99 *vs* 36.46 (p = 0.675)		–		63.88 *vs* 77.50 (p = 0.377)		61.81 *vs* 71.88 (p = 0.628)		–		56.66 *vs* 58.68 (p = 0.904)	
– Airway (no *vs* yes)	27.29 *vs* 62.98 (p = 0.008)†		–		65.36 *vs* 65.00 (p = 0.968)		49.72 *vs* 73.52 (p = 0.045)†		–		44.36 *vs* 68.21 (p = 0.008)†	
– Genetic (no *vs* yes)	53.07 *vs* 8.33 (p < 0.001)†		–		67.15 *vs* 53.33 (p = 0.283)		65.07 *vs* 42.50 (p = 0.271)		–		60.83 *vs* 32.99 (p = 0.036)†	

†statistically significant value. HRQoL = health-related quality of life; CVS = cardiovascular

Table 3. Multiple linear regression analyses to assess the contribution of variables to Pediatric Quality of Life Inventory

Variable	Not ventilator-dependent								Ventilator-dependent							
	Physical functioning		Emotional functioning		Social functioning		Total paediatric HRQoL		Physical functioning		Emotional functioning		Social functioning		Total paediatric HRQoL	
	β	*P*-value	β	*P*-value	β	*P*-value	β	*P*-value	β	*P*-value	β	*P*-value	β	*P*-value	β	*P*-value
Duration	−0.374*	0.032*	−0.246	0.202	−0.480*	0.010*	−0.400*	0.027*	−0.170	0.544	−0.212	0.604	0.096	0.722	−0.144	0.579
Co-morbidities																
- Pulmonary disease	−0.027	0.877	−0.072	0.720	−0.082	0.651	−0.046	0.798	−0.494*	0.014*	−0.189	0.462	−0.372*	0.046*	−0.457*	0.014*
- Neurological disease	−0.349	0.053	−0.142	0.476	−0.314	0.090	−0.316	0.088	−0.075	0.707	−0.343	0.253	−0.370	0.078	−0.255	0.185
- CVS disease	0.283	0.111	0.204	0.308	0.264	0.151	0.272	0.138	0.010	0.971	0.119	0.762	−0.049	0.849	−0.025	0.921
- Endocrine disease	0.040	0.803	−0.032	0.864	−0.117	0.487	−0.030	0.859	−0.148	0.486	0.313	0.320	0.297	0.165	0.065	0.740
- Airway disease	−0.005	0.978	−0.390	0.077	−0.068	0.727	−0.168	0.388	0.565	0.050	−0.172	0.655	0.044	0.859	0.383	0.137
- Genetic syndrome	−0.309	0.076	−0.048	0.805	−0.154	0.382	−0.270	0.132	−0.274	0.196	−0.299	0.326	−0.093	0.609	−0.208	0.284
Living outside Jeddah	–	–	–	–	–	–	–	–	−0.071	0.712	−0.349	0.232	0.376	0.064	0.066	0.712
- Home visit	–	–	–	–	–	–	–	–	0.170	0.395	0.084	0.771	0.558*	0.011*	0.401*	0.046*

β = standardised beta; HRQoL = health-related quality of life; CVS = cardiovascular

of care for parents with similar responsibilities.[51] Many studies have described training, assistance and psychosocial support programmes for parents caring for a child with a tracheostomy,[10,13,16] and there appears to be a great need for such programmes.[10,15]

- Only a few studies have assessed quality of life (QoL) in children with tracheostomies, especially in the Middle East and North Africa
- It has been previously shown that the QoL in children with tracheostomies is lower than in healthy children and in children with many other morbid conditions
- This study shows effects of duration of tracheostomy on QoL in these children
- This study quantitively and comparatively shows the benefits of home nursing visits on QoL for ventilator-dependent patients
- In ventilator-dependent children, the presence of pulmonary diseases worsens QoL

The socioeconomic factors in our study were also similar to previous findings in that they did not appear to influence family or child QoL, indicating that tracheostomy in children influences QoL at comparable levels within the spectrum of educational status or other socioeconomic determinants.[10,12,49]

Although this study provides insightful findings and useful recommendations in clinical practice drawn from children with tracheostomy and their parents from two centres, several limitations need to be acknowledged. First, some aspects of a child's QoL were not covered in the current study, such as sleep quality. Previous work by Hopkins *et al.*[9] showed that tracheostomy affects patients' sleep quality. Second, despite the moderate sample size, and despite the sample being from two large tertiary centres, generalisation of the findings should be approached with caution. Furthermore, minimal inferences, if any, can be made about the results in terms of QoL in children in the intensive care unit because none from the sample were in the intensive care unit.

Conclusion

This is the first study from the Middle East and North Africa region to assess QoL in children with a tracheostomy and its impact on parents. Furthermore, it is the first study to demonstrate QoL benefits from routine home visits to ventilator-dependent children by a professional team. The longer the duration of tracheostomy, the worse social functioning and overall QoL are. Future research should focus on testing family support programmes.

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