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Factors affecting the quality of life of caregivers of children with tracheostomy: an assessment tool

Cover figure. Child with a tracheostomy who is living with her parents as primary caregivers.

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Summary

Objectives. Develop and validate comprehensive questionnaire scales to investigate the quality of life (QoL) of parents caring for tracheostomised children and identify potential contributing factors.

Methods. This is a cross-sectional questionnaire conducted in paediatric otolaryngology clinics in 5 tertiary hospitals. Caregivers caring for children with tracheostomies at home between April 2023 and March 2024 were included. The survey items were divided into 4 distinct domains: (1) frequency of healthcare utilisation; (2) awareness and knowledge; (3) skills in tracheostomy care; and (4) caregiver's QoL. Internal consistency, construct validity, and test-retest reliability were assessed.

Results. Eighty-seven caregivers completed the survey. The combined Cronbach's α coefficient was 0.81. Exploratory factor analysis values exceeded 0.75 for most items. The awareness level, ease of obtaining tracheostomy tubes, and experience in tracheostomy care showed a significant positive association with the QoL.

Conclusions. TrachQoL questionnaire is a reliable tool that may help guide clinical interventions and future research. Scales for caregivers' level of knowledge and skills and accessibility to healthcare services are useful for investigating QoL in families caring for children with a tracheostomy.

Key words: tracheostomy, quality of life, questionnaire, caregiver, pediatric

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Introduction

Tracheostomy is a common procedure in paediatric patients with potentially life-threatening respiratory compromise. It is performed on children who require prolonged mechanical ventilation (MV), have upper airway anomalies, or have significant comorbid conditions, including neurologic impairment and chronic lung diseases [1-4]. The age distribution of patients undergoing tracheostomy varies, with most children undergoing tracheotomy within the first year of life. Children younger than 2 years of age are at higher risk of early postoperative complications, including pneumonia, sepsis, and mortality [5,6]. The duration for tracheostomy tube insertion to decannulation in paediatric patients varies widely, with studies reporting median durations ranging from 4.7 to 25 months [7,8].

Children can be discharged with a tracheostomy (Cover figure). Although it brings positive transformation to growth, development, and phonation, managing a tracheostomised child at home can be challenging and demanding for caregivers. The reason might be linked to the overwhelming responsibility and common unexpected events, such as accidental decannulation, delays in recognising and clearing secretions, or ventilator malfunctions [9]. Another factor is the lack of anticipatory guidance and education for common clinical scenarios to prepare caregivers after transitioning children from hospital to home care. Together, these challenges are often stressful and negatively impact the caregivers' quality of life (QoL), affecting their physical, emotional, psychological, and economic well-being [10].

Most existing tools either lack specificity or do not explore the relationship between caregivers' QoL and contributing factors such as knowledge, confidence, and healthcare access. To bridge the gap, this study aims to develop and validate a novel, multi-domain, self-reported tool – TrachQoL – designed specifically to assess the QoL of caregivers of children with tracheostomies. By capturing practical and emotional caregiving experiences, this tool can support future research, guide tailored interventions, and improve caregiver support systems.

Materials and methods

Participants

Children who had a tracheostomy at the time of study conduction and were receiving care at home were recruited from hospital databases in 5 tertiary hospitals from April 2023 to March 2024. Patients who were decannulated, deceased, or receiving care in home health care services were excluded. Caregivers of eligible children were asked to fill the questionnaire in an electronic format using QuestionPro software.

Phase 1: tool development and conceptual framework

To align with the study's aim of developing and validating a comprehensive tool to assess caregivers' QoL for children with tracheostomies, this section outlines the systematic process followed in designing the TrachQoL questionnaire. The primary objective was to create a multi-domain instrument that captures the emotional, practical, and knowledge-based challenges faced by caregivers. The methodology was structured to ensure each domain reflects a critical aspect of caregiver experience, from healthcare utilisation to emotional well-being and tracheostomy management skills.

To develop the TrachQoL questionnaire, 3 key resources were utilised: (1) a comprehensive literature review of epidemiological data and existing questionnaires, (2) observations and semi-structured interviews with caregivers of children who had undergone tracheostomy, and (3) expert input from senior paediatric otolaryngologists obtained through semi-structured interviews. These interviews were designed to be as thorough as possible, providing valuable insights into the structure and content of the questionnaire domains. Discussions with caregivers focused on identifying key factors affecting their QoL, while consultations with physicians highlighted the challenges they observed and the essential knowledge and skills caregivers need for effective, independent tracheostomy management at home. The items collected were subsequently compared with existing questionnaires, reviewed for relevance, and refined for clarity and appropriateness.

Phase 2: item selection and scoring

The outcome of this process was a carefully designed questionnaire to evaluate children with tracheostomies across 4 key domains:

Domain 1. Frequency of healthcare utilisation: this domain captures the frequency of visits to otolaryngology clinics and emergency departments, hospital admissions due to tracheostomy-related complications, and the feasibility of obtaining tracheostomy-related tools within the past 3 months.

Domain 2. Awareness and knowledge about tracheostomy: this domain assesses caregivers' understanding of essential care measures and their confidence in managing tracheostomy-related situations. It consists of 10 structured statements to be categorised as correct, incorrect, or do not know. Awareness levels were classified as poor (0-59% correct responses), moderate (60-79%), or very good (80-100%). Additionally, caregivers were asked to self-evaluate their knowledge using a 5-point Likert scale, with scores of 1-2 indicating "poor", 3 indicating "neutral", and 4-5 indicating "very good".

Domain 3. Skills and confidence in tracheostomy care: this domain evaluates caregivers' proficiency in performing specific care tasks, such as suctioning secretions, cleaning the tracheostomy site, changing the tracheostomy tube, and responding to emergencies. Caregivers also self-assessed their expertise using a 5-point Likert scale, scored in the same way as Domain 2.

Domain 4. Caregiver's QoL: this domain examines challenges faced by caregivers over the past 4 weeks, with each item rated on a 5-point Likert scale. Scores of 1-2 indicate that the challenge is "applicable", 3 is "neutral", and 4-5 signify it is "not applicable". At the end of this domain, caregivers self-evaluate their overall QoL on the same scale, with 1-2 indicating "poor", 3 indicating "neutral", and 4-5 indicating "very good".

As the primary objective was to explore relationships between each domain and caregivers' QoL, a composite score across all domains was neither calculated nor used for data interpretation. The assessment tool is provided in Appendix 1.

Figure 1. Histogram showing age distribution (in months) at tracheostomy.

Phase 3: validation and statistical analysis

Multiple statistical techniques were used to assess the tool's reliability, validity, and structure. Descriptive statistics summarised the demographic and clinical variables, including age, gender, and healthcare utilisation. Ceiling and floor effects were evaluated for each domain to detect potential response biases.

Internal consistency was assessed using Cronbach's α, with values > 0.70 considered acceptable. Construct validity was examined through Exploratory Factor Analysis (EFA) with varimax rotation. Factors were retained based on eigenvalues > 1 and scree plot inspection. Test-retest reliability was evaluated using Cohen's kappa on data collected 3 weeks apart. Principal Component Analysis (PCA) was also performed to confirm domain structure. Chi-square tests assessed associations between categorical variables, with Cramer's V used for effect size. All analyses were conducted using Python, with p values < 0.05 considered significant.

Results

A total of 87 caregivers, of 87 children, participated with no missing data. Children had a nearly balanced gender distribution (54% males, 46% females). Most tracheostomies occurred after 2 months of age (92%), with 48% between 2-12 months and 44% after 12 months (Fig. 1).

Distribution/ceiling and floor effects

The analysis of the ceiling and floor effects for the four domains revealed varied results. In domain 1, significant floor

Table I. Reliability analysis (Cronbach's α values).

Domains	Cronbach's α
Overall	0.81
Domain 1	0.80
Domain 2	0.79
Domain 3	0.94
Domain 4	0.92

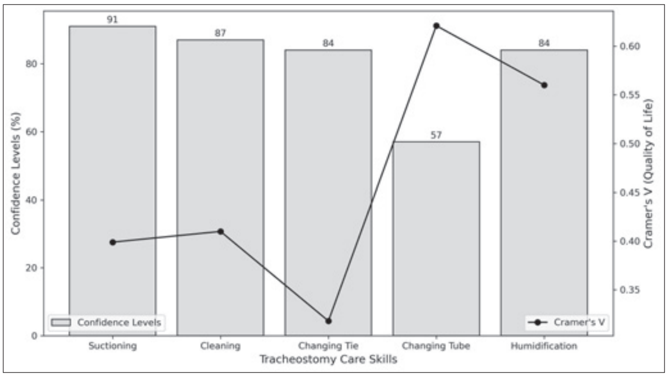

Figure 2. Correlations between confidence in tracheostomy care and quality of life.

effects were observed, with a high percentage of respondents reporting minimal healthcare utilisation related to tracheostomy care. Domain 2 exhibited minimal floor effects and some ceiling effects. Domain 3 displayed significant ceiling effects for many items, with a high percentage of respondents reporting maximum confidence and skills in providing tracheostomy care. Domain 4 exhibited both ceiling and floor effects related to anxiety and mental health.

Reliability

The reliability of the survey items within each domain was assessed using Cronbach's α. Domains 1 and 2 exhibited good internal consistency with a Cronbach's α of 0.80 and 0.79, respectively. Domains 3 and 4 demonstrated excellent internal consistency with a Cronbach's α of 0.93 and 0.92, respectively. The overall Cronbach's α across all 4 domains was found to be 0.81, indicating good internal consistency for the survey (Tab. I).

Construct validity

The EFA revealed that most items had robust factor loadings, with values exceeding 0.75, indicating strong correlations between the items and their respective factors.

Principal component analysis (PCA)

PCA was conducted to examine the underlying structure within each domain. In domains 1 and 4, the scree plots indicated that the first few components accounted for most of the variance. Similar patterns were observed in domains 2 and 3, with the first component explaining a substantial proportion of the variance.

Test-retest reliability

Test-retest reliability was assessed in 31 participants approximately 3 weeks apart. Most items showed high consistency, with correlation coefficients ranging from 0.75 to 0.97. The total awareness score demonstrated strong reliability ($r = 0.91$), and high correlations were also observed for items assessing caregiver confidence and skills ($r = 0.92$).

Association analysis of tracheostomy care factors and QoL

The association between the ease of obtaining a tracheostomy tube and QoL was significant (Cramer's V = 0.399, p value = 0.020). The overall awareness level showed a positive association with QoL (Cramer's V = 0.680, p value = 0.001). The association between skills in tracheostomy care and QoL was also strong (Cramer's V = 0.687, p value < 0.001) and Figure 2 demonstrates their correlation. Furthermore, the association between the skill in dealing with tracheostomy-related situations and QoL was very strong (Cramer's V = 0.675, p value < 0.001).

This study demonstrated that the TrachQoL questionnaire is a reliable and valid tool for assessing caregiver QoL in the context of pediatric tracheostomy. The instrument showed strong internal consistency, high test-retest reliability, and robust construct validity across its 4 domains. Ceiling and floor effect analyses highlighted variability in responses, particularly in caregiver-reported confidence and emotional burden. Access to tracheostomy supplies, awareness, and caregiving skills were significantly associated with caregivers' QoL, underscoring the relevance of the tool in identifying areas for support.

Discussion

In this study, we developed and validated a novel instrument to measure the QoL and its determinants among caregivers of children with tracheostomies. The questionnaire demonstrated strong reliability and validity in assessing caregiver knowledge, confidence in tracheostomy care, and access to healthcare resources. Beyond its primary application, the tool can be used in longitudinal studies to evaluate the impact of different interventions. Moreover, wider dissemination of the queationnaire may provide valuable epidemiological insights.

The items were developed through literature review, direct clinical observations, and semi-structured interviews with caregivers and paediatric otolaryngology experts. Domains were initially grouped based on clinical judgment and further supported by statistical analyses. Each domain was scored separately and correlated with others to emphasise qualitative insights over a composite scoring system.

Caregivers of tracheostomy patients experience significant physical, emotional, and financial challenges, reinforcing the need for routine QoL assessments in this population [11]. The reported findings in our study align with those of Wynings et al. who observed that caregivers of tracheostomised children had persistently lower QoL scores, especially during the early post-discharge phase [12]. Despite a growing number of tools, few are tailored specifically to tracheostomy caregiving contexts, and longitudinal validation remains limited [13]. Having a more detailed tool would significantly provide actionable insights.

Currently available tools, such as the PedsQL ™ Family Impact Module, assess general family functioning but do not address the unique challenges of tracheostomy care [14]. These include routine procedures like suctioning and emergency management, as well as social and psychological stressors [15,16]. Other instruments, such as the Pediatric Tracheotomy Health Status Instrument, offer insight into symptom burden and caregiver QoL but may not fully capture the link with caregivers' knowledge and confidence in managing their child's condition [17].

Our tool may help clinicians design tailored interventions – such as caregiver training programmes, improved access to supplies, and psychosocial support – that directly address factors impacting QoL. To ensure generalisability, the tool's validity and reliability were tested across multiple institutions.

This study is limited by a relatively small sample size, reflecting the low number of eligible cases rather than recruitment constraints. The lack of regional epidemiological data and variability in healthcare systems, caregiver training protocols, and available tracheostomy care tools may influence caregiver experiences and limit international comparability. Additionally, responses may be subject to recall or social desirability bias. Variations in surgical techniques and institutional practices across centres could also impact caregiver perceptions. Future research should investigate these factors more comprehensively to enhance the generalisability of the tool. Nonetheless, broader collaboration across tertiary centres could expand its applicability and contribute valuable population-level insights.
Although a formal pilot study was not conducted, this initial deployment serves as formative evaluation and provides a foundation for future refinement. Further research should explore longitudinal changes in QoL and the effectiveness of targeted interventions, such as educational campaigns and the use of mobile health technologies. Ultimately, this tool can guide clinicians and policymakers in delivering more responsive, culturally sensitive care to children with tracheostomy and their families.

Conclusions

The TrachQoL is a valid and reliable tool specifically designed to assess the QoL of families caring for children with tracheostomy. This tool can support clinical decision-making, guide targeted interventions, and serve as a foundation for longitudinal studies evaluating the impact of structured support programs. To enhance its generalisability and inform health policy development, future multicentre studies with larger and more diverse populations are recommended.

Conflict of interest statement

The authors declare no conflict of interest.

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Author contributions

AA, HA, AAl, DA: questionnaire formulation; DA, AAl, NA, LA, BA: data interpretation and the first draft of the manuscript. All authors reviewed, commented on previous versions of the manuscript, contributed to the study conception and data collection, read and approved the final manuscript.

Ethical considerations

This study was approved by Imam Abdulrahman bin Faisal University (protocol number IRB-2023-01-279) the King Abdullah International Medical Research Center (KAIMRC) (protocol number RYD-23-419812-171959).

The research was conducted ethically, with all study procedures being performed in accordance with the requirements of the World Medical Association's Declaration of Helsinki. Written informed consent was obtained from each participant/patient for study participation and data publication. All questionnaires were completed anonymously.

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Appendix A

Supplementary Table I. Pediatric TrachQoL questionnaire.

Hospital visits and medical needs.
During the past 3 months, how many times have you visited the ENT clinic for a problem related to the tracheostomy?
To choose one of the following:
Never (I have not visited the clinic for a problem during the past 3 months)
1-2 times
3-4 times
5-6 times
More than 6 times
During the past 3 months, how many times have you taken your child to the emergency department for a problem related to the tracheostomy?
To choose one of the following:
Never (I have not taken my child to the emergency department during the past 3 months)
1-2 times
3-4 times
5-6 times
More than 6 times
During the past 3 months, how many times has your child been admitted to the hospital due to complications attributed to tracheostomy?
To choose one of the following:
Never (my child was not admitted to the hospital because of the tracheostomy during the past 3 months)
1 time
2 times
3 times
4 times
More than 4 times
During the past 3 months, assess how easily you obtained the necessary tools for tracheostomy care:
1. Tracheostomy tube
2. Humidifier
3. Suction device
4. Tube tie
(Likert scale 1-5: 5 = very easy, 1 = very difficult)
Do you think that the tracheostomy tube may be a major reason for the deterioration of your child's health?
(Likert scale 1-5: 5 = Totally disagree, 1 = Totally agree)
1. Awareness level of general information about tracheostomy
From your perspective, evaluate the following concepts related to children who have undergone tracheostomy:
1. The child can swim in bathing pools or the sea like other children
2. It is recommended to wear high-collared shirts to cover the breathing tube opening
3. The child cannot go to school alone because he/she constantly needs care
4. The older the child gets, the less his need for suctioning secretions
5. The child can speak despite the presence of a tracheostomy tube
6. The tracheostomized child cannot eat by mouth and needs to be fed through a tube
7. It is recommended to clean the neck and change the tube tie once a day
8. When the tube is completely out of the opening, it should not be pushed back into place
9. If you notice general disturbance and agitation with an increase in respiratory rate in a tracheostomized child, you should avoid home first aid and go directly to the hospital
10. The child must be brought to the emergency room if the temperature rises, blood comes out of the tube, or the color or smell of the secretions changes

▶

Supplementary Table I. *continues.*

To choose one of the following:
Correct statement
Wrong statement
I am not sure
Taking into account the information you know about the tracheostomy and proper care of a tracheostomized child, how do you evaluate your level of experience now in general?
(Likert scale 1-5: 5 = Excellent, 1 = Very poor)
2. Tracheostomy care
Evaluate from your point of view the extent to which you are qualified and prepared to provide the necessary care for your child in the following aspects:
1. I believe that I am able to suction secretions from the tube by following the correct steps
2. I believe I am able to clean the skin around the tracheostomy opening and ensure that the opening remains dry and clean
3. I believe that I can change the tube tie by following the correct steps and avoiding the tube coming out of place
4. I believe that I am able to change the tracheostomy tube carefully and by following the correct steps without causing suffocation to my child
5. I believe that I am able to use air humidification methods for my child, such as a humidifier mask and a heat and moisture exchanger (HME)
(Likert scale 1-5: 5 = I know exactly how to do it, 1 = I am not capable of doing it at all)
Please rate your level of coping with the following general life aspects of your child:
1. I can feed my child safely and know how to act correctly if food enters the windpipe
2. I can deal with my child while bathing, and I know how to act correctly if soap or water gets inside the tracheostomy tube
3. I always make sure to provide a safe environment for my child while sleeping, and I make sure to provide an audio or video recorder if I am not in the room with him
(Likert scale 1-5: 5 = Excellent, 1 = Very poor)
Please rate your level of confidence and calm in responding to emergency situations below that require urgent intervention to save your child's life:
1. I can notice if the amount of secretions has increased and suction them safely
2. I can notice the symptoms of abnormal breathing that indicate a blocked tube, and I deal with them quickly and safely to avoid my child suffocating
3. I take the correct and safe action when the tube comes out of its place, and I have a bag that contains the spare tube
4. I can deal with bleeding from the tracheostomy opening, whether it is inactive bleeding or active bleeding
5. I am aware of the cases that require medical intervention and therefore I can provide urgent medical care for my child when they occur
6. I know the steps of cardiopulmonary resuscitation by heart, and I am prepared to do it correctly for my child with a tracheostomy tube in place (if his condition requires it)
(Likert scale 1-5: 5 = I am completely confident in this situation, and I remain completely calm, 1 = I am not at all confident in my ability to save my child in this situation, and I may feel panic and fear)
Overall, how do you rate your skill in dealing with everyday situations and emergency situations related to tracheostomy?
(Likert scale 1-5: 5 = Excellent, 1 = Very poor)
3. Parental quality of life after tracheostomy
Please answer the questions regarding your concern for your child's safety based on events over the past 4 weeks:
1. How often were you worried or afraid for your child's safety while changing the breathing tube?
2. How many times have you been worried or afraid for your child's safety while suctioning secretions?
3. How often have you been worried or afraid for your child's safety in terms of his ability to breathe in general?
4. How many times during the past week were you able to take your child out of the house (i.e. to finish duties or hang out)?
(Likert scale 1-5: 5 = Never, 1 = Always)
Please answer questions about your mental health based on events happened over the past 4 weeks:
1. Has your child's condition affected your mental health negatively?
2. Has your child's condition affected your social relationships negatively?
3. Has your child's condition affected the quality of your performance at work/home tasks negatively?
4. Has your child's condition affected sleep sufficiently negatively?
(Likert scale 1-5: 5 = Never, 1 = Always)
Taking into account the information you know about your child's condition and measures to care for him, how do you evaluate your quality of life during the past four weeks in general?
(Likert scale 1-5: 5 = Excellent, 1 = Very poor)